

AN INVESTIGATION OF TYPES AND AWARENESS OF PSYCHOLOGICAL  
PROBLEMS OF MALE ADOLESCENTS WITH AUTISM SPECTRUM  
DISORDERS WHO HAVE BEEN TREATED FOR  
PSYCHIATRIC DISORDERS

by

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## ABSTRACT

This study examined types of psychological and functioning problems, and awareness of these problems, in adolescents with Autism Spectrum Disorders (ASD) who had been treated for comorbid psychiatric disorders. Participants were male adolescents, ages 11-18, who were “high functioning” ( $IQ > 85$ ). The ASD group consisted of 26 adolescents, diagnosed with ASD and a comorbid psychiatric disorder, and their parents. The control group included 26 adolescents, without ASD or any psychiatric disorders, and their parents. Adolescents and parents completed the Achenbach System of Empirically-Based Assessment (ASEBA) and the Rating of Functioning. Parents also completed a developmental history interview. Comparisons were made between parents and adolescents and between ASD and control groups.

Anxiety (58%), depression (54%), and Attention Deficit Hyperactivity Disorder (ADHD) (46%) were reported as common comorbid diagnoses among ASD participants. In the ASD group, parent-report of psychological problems was significantly higher than the self-report on the ASEBA (Total scale  $t(25) = 3.34, p = 0.003, d = 0.66$ ). On the other hand, there was no significant difference between parent- and adolescent-report of symptoms in the control group (Total scale  $t(25) = -1.36, p = 0.187, d = -0.27$ ). Even though adolescents with ASD had received treatment for psychiatric disorders, both adolescent and parent scales on the ASEBA were elevated.

Endorsement of symptoms on the ASEBA suggests that despite treatment, psychological problems persisted in adolescents with ASD.

On the Rating of Functioning, all informants expected adolescents to have better functioning in the future. Parents in the ASD and control groups predicted that their children would have significantly higher functioning 6 months in the future compared to levels of current functioning (ASD Group Parents  $t(25) = 4.66, p < 0.001, d = 0.89$ ; Control Group Parents  $t(25) = 5.73, p < 0.001, d = 1.09$ ). Adolescents in both groups predicted the same increase in functioning (ASD Group Adolescents  $t(25) = 7.59, p < 0.001, d = 1.44$ ; Control Group Adolescents  $t(25) = 4.84, p < 0.001, d = 0.92$ ).

Adolescents with ASD had elevated scores on all scales of the ASEBA and reported more everyday functioning problems than control group adolescents. Additionally, adolescents and their parents both reported the highest functioning at school, then at home, and last socially. This demonstrates that adolescents with ASD were able to report their behavior problems even though they report fewer problems than their parents.

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## TABLE OF CONTENTS

ABSTRACT .....	iii
ACKNOWLEDGMENTS .....	viii
CHAPTERS	
I: INTRODUCTION.....	1
Epidemiology of ASD .....	1
Psychiatric Disorders .....	3
Psychological and Social Outcome .....	16
Awareness of Psychological Problems in Adolescents with ASD .....	18
Self and Other Reports of Psychological Problems.....	21
Studies Examining Psychopathology and Everyday Functioning .....	24
Purpose of the Study .....	26
Research Hypotheses and Questions .....	27
II: METHODS .....	30
Recruitment.....	30
Participants .....	31
Data Collection Procedures .....	32
Measures .....	33
Data Analysis.....	42
III: RESULTS .....	47
Characteristics of Participants .....	47
Research Hypothesis 1 .....	59
Research Hypothesis 2 .....	63
Research Hypothesis 3 .....	65
Research Hypothesis 4.....	67
Research Hypothesis 5.....	68
Research Hypothesis 6.....	69
Research Question 1 .....	70
Research Question 2 .....	89

IV: DISCUSSION .....	92
Comorbid Psychiatric Disorders.....	92
Awareness of Problems .....	95
Implications for Practice.....	100
Limitations .....	102
Future Research .....	104
Summary .....	105
APPENDICES	
A: ASD AND CONTROL FLYERS .....	106
B: ASD GROUP: ADULT CONSENT, PARENT PERMISSION, AND ADOLESCENT ASSENT FORMS .....	109
C: CONTROL GROUP: ADULT CONSENT, PARENT PERMISSION, AND ADOLESCENT ASSENT FORMS .....	119
D: RATING OF FUNCTIONING: ADOLESCENT AND PARENT FORMS.....	129
E: PARENT INTERVIEW .....	138
REFERENCES .....	149



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## CHAPTER I

### INTRODUCTION

Social, language, and behavioral deficits are common among adolescents with autism spectrum disorders (ASD); however, these adolescents also oftentimes suffer from comorbid psychiatric disorders and psychological problems. Some research has been conducted into psychological problems that are often comorbid with ASD, but few studies have examined the awareness of psychological and adaptive functioning of adolescents with ASD. The current study is intended to help better understand the level of awareness of psychological problems and functional ability among a population of male adolescents with “high-functioning” ASD who have been treated for psychiatric disorders.

#### Epidemiology of ASD

ASDs are increasingly prevalent in the general population and are an important public health concern. The latest epidemiological report states that 1 in 88 children, aged 8 years, have ASD (Centers for Disease Control and Prevention (CDC), 2012). This definition of ASD includes Autistic Disorder, Pervasive Developmental Disorder-Not Otherwise Specified (PDD-NOS), and Asperger’s Disorder. The new rate

represents an increase of 23% from the prevalence estimates of 1 in 110 in 2006. Increase in prevalence was similar for males and females (CDC, 2012). Furthermore, current prevalence estimates represent an increase of 78% from the rate of 1 in 156 in 2002. These prevalence rates are generally consistent with prevalence estimates reported in other studies although some international rates have been higher (CDC, 2012). The steadily increasing prevalence demonstrates the need to study characteristics of individuals with ASD in order to help this increasing population.

Examination of specific subgroups demonstrates variability in prevalence by demographic variables. Current estimates show that males continue to have a higher prevalence (1 in 54) than females (1 in 252). Additionally, non-Hispanic White children (1 in 83) had a significantly higher prevalence rate than Hispanic children (1 in 98) and non-Hispanic Black children (1 in 126) (CDC, 2012). These prevalence rates show that ASDs continue to affect many children, although rates vary by sex and ethnicity.

Epidemiological survey also indicates that identification of children with ASDs is improving. Seventy-nine percent of all children identified as having an ASD by epidemiological survey had previously had an ASD diagnosis. This is the highest proportion of children with an ASD diagnosis in CDC epidemiological surveys, which suggests that providers are able to increasingly identify children with ASD (CDC, 2012). However, 20% of the children who were previously diagnosed had multiple different ASD diagnoses across evaluations, suggesting ASD subtype may vary by evaluation. Age of first ASD diagnosis varied by ASD subtype since the median age of Autistic Disorder diagnosis was 48 months, age of PDD diagnosis was 53 months, and

age of Asperger's Disorder diagnosis was 75 months. Finally, cognitive ability varied among children identified with an ASD by the epidemiological survey. Thirty-eight percent of the children were classified as having an intellectual disability, 24% were in the borderline range (IQ 71-85), and 38% had an IQ greater than 85. Epidemiological survey data demonstrate that children with ASDs are increasingly diagnosed although they differ in age of first diagnosis, the stability of their diagnosis, and their cognitive ability.

### Psychiatric Disorders

#### Comorbid Disorders

Disorders and symptoms that have been reported in individuals with ASD include Attention Deficit Hyperactivity Disorder (ADHD), anxiety, compulsive behaviors, obsessions, Obsessive-Compulsive Disorder (OCD), sleep problems, mood disorders, and psychotic disorders (Hofvander et al., 2009; Leyfer et al., 2006; Tsai, 1996). The rates of comorbid disorders vary by study; however, individuals with ASD are consistently reported as having high rates of comorbidity, as seen in Table 1.

Even though differing rates of psychiatric disorders have been found among study populations, individuals with ASD have consistently been found to have significant comorbid mood disorders (including depression), anxiety, and ADHD. Among Arab children with ASD, clinical interview identified 58.3% with anxiety disorders, 31.6% with ADHD, and 23.3% with Conduct Disorders (CD) (Amr, Raddad, El-Mahesh, Bakr, Sallam, & Amin, 2012). Other researchers have found that 10% of

Table 1

*Studies Examining Comorbid Psychiatric Disorders and Psychological Problems Since 2005*

Author(s)	Year	Age	# of ASD Participants/ Nationality	Procedures	Prevalence of Psychiatric Diagnoses/Psychological Problems Reported
Amr, Raddad, El-Mahesh, Bakr, Sallam, & Amin	2012	6-11	60/ Arab	Semistructured clinical interview for children/ No control	Any Disorder (63.3%), Anxiety (58.3%), ADHD (31.6%), Conduct Disorder (23.3%), Depression (13.3%)
Ooi, Tan, Lim, Goh, & Sung	2011	6-18	71/ Singapore	CBCL/ No control	Percent above clinical cutoff: Anxious/Depressed (26.8%), Withdrawn/Depressed (40.8%), Somatic Complaints (14.1%), Social Problems (60.6%), Thought Problems (50.7%), Attention Problems (49.3%), Rule-breaking Behavior (12.7%), Aggressive Behavior (25.4%)
Hess, Matson, & Dixon	2010	4-16	137/ American	Autism Spectrum Disorders-Comorbid for Children (a parent rating scale)/ No control	Behavior scales significantly higher for youth with ASD : Worry/Depressed, Under-eating, Over-eating, Avoidant Behavior, and Repetitive
Joshi et al.	2010	3-17	217/ American	KSADS/ Clinical Comparison	ADHD (83%), Specific Phobia (79%), Separation Anxiety (79%), Generalized Anxiety (76%), Social Phobia (60%), Depression (56%), Bipolar 1 (31%), OCD (25%), Tic Disorder (23%), Conduct Disorder (22%)
Levy et al.	2010	8	2,568/ American	Records review with abstracted data/ No control	Any Disorder (10%), ADHD (21.3%), ODD (4.0%), Anxiety (3.4%), OCD (2.0%), Depression (1.1%), Bipolar (0.7%), Psychosis (0.3%), Conduct Disorder (0.2%)
Mattila et al.	2010	9-16	50/ Finnish	KSADS/ No control	Anxiety (42%), ADHD (38%), Tic Disorders (26%), ODD (16%), Depression (6%), Conduct Disorder (2%)

Table 1 (*continued*)

Author(s)	Year	Age	# of ASD Participants/ Nationality	Procedures
Hurtig et al.	2009	11-17	47/ Finnish	CBCL, TRF, YSR/ Control group from local schools
Kanne, Abbachi, & Constantino	2009	3-18	177/ American	ASEBA CBCL & TRF DSM scales/ Comparison group of male siblings
Simonoff et al.	2008	10-13	112/ British	Child and Adolescent Psychiatric Assessment/ No control
de Bruin, Ferdinand, Meester, de Nijs, & Verheij	2007	6-12	94/ Dutch	DISC-IV-P (Structured Interview)/ No control
Holtmann, Bolte, & Poustka	2007	4-20	46/ German	German CBCL/ Compared males and females with ASD, No control

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## Prevalence of Psychiatric Diagnoses/Psychological Problems Reported

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Parent and adolescent scores in ASD group: Strong positive correlation on Somatic Complaints, Social Problems, Delinquent Behavior, Aggressive Behavior, and Externalizing.

Adolescents with ASD reported more problems than parents on: Anxious/Depressed, Thought Problems, and Total scales

CBCL DSM scales: Affective Problems (26%), Anxiety Problems (25%), Somatic Problems (6%), Attention Deficit/Hyperactivity Problems (25%), Oppositional Defiant Problems (15%), Conduct Problems (16%), Pervasive Developmental Problems (68%)

Any Disorder (70.8%), Social Anxiety Disorder (29.2%), ADHD (28.1%), ODD (28.1%), Generalized Anxiety Disorder (13.4%), Panic Disorder (10.1%), Conduct Disorder (3.2%), Major Depressive Disorder (0.9%),

Any Disorder (80.9%), Anxiety (55.3%), ADHD (44.7%), ODD (37.2%), Major Depression (10.6%), Conduct Disorder (9.6%), OCD (6.4%)

Females had more social, attention, and thought problems than males.

Mean scale scores for males: Social Withdrawal (66.9), Somatic Complaints (54.8), Anxious/Depressed (69.4), Social Problems (66.0), Thought Problems (70.0), Attention Problems (68.4), Delinquent Behavior (61.0), Aggressive Behavior (58.6), and Total (67.5)

Table 1 (*continued*)

Author(s)	Year	Age	# of ASD Participants/ Nationality	Procedures	Prevalence of Psychiatric Diagnoses/Psychological Problems Reported
Leyfer et al.	2006	5-17	109/ American	Autism Comorbidity Interview- Present and Lifetime Version (modified KSADS)/ No control	Specific Phobia (44.3%), OCD (37.2%), ADHD-Inattentive (20%), Depression (10.1%), Social Phobia (7.5%), ODD (7.1%), Generalized Anxiety (2.4%), Bipolar 1 (1.9%), Bipolar 2 (0.9%)
Pearson et al.	2006	4-17	51/ American	Personality Inventory for Children-Revised/ No control	Autism Group: Depression (54%), Anxiety (38%), Hyperactivity (31%), Delinquency (23%), Somatic Concern (15%)  PDD Group: Depression (56%), Anxiety (52%), Hyperactivity (28%), Delinquency (20%), Somatic Concern (8%)
Gadow, DeVincent, Pomeroy, & Azizian	2005	6-12	301/ American	Child Symptom Inventory 4 (parent and teacher)/ Clinical comparison, special education students, and regular education students groups	Males: ADHD (59.2), ODD (27.8), Generalized Anxiety (25.2), Dysthymia (12.0%), Separation anxiety (6.7), and Major depression (6.2)  Female: ADHD (66.7), ODD (26.8%), Generalized Anxiety (19.5%), Separation anxiety 97.1%), Dysthymia (7.1%), Major Depression (2.4%)  Overall: Severity of symptoms of ADHD, ODD, GAD, separation anxiety disorder, and depressive disorder in ASD group was comparable to children referred for outpatient psychiatric evaluation.

*Notes: KSADS = Kiddie Schedule for Affective Disorders and Schizophrenia, CBCL = Child Behavior Checklist, TRF = Teacher Report Form, YSR = Youth Self Report..*

*If present and lifetime prevalence rates were given for a disorder, the present rates were used.*



8-year-old children with ASD had one or more psychiatric disorders, with Oppositional Defiant Disorder (ODD), anxiety disorder, mood disorder, and OCD being the most common (Levy et al., 2010). Hofvander et al. (2009) found that in adults with ASD 53% had a mood disorder, and 43% were diagnosed with ADHD. Pearson et al. (2006) had similar results and reported clinically significant levels of depression in half of the children and adolescents studied. In contrast, other researchers have found specific phobia to be the most common comorbid disorder in ASD with rates as high as 44% (Leyfer et al., 2006). While the rates of psychiatric disorders vary by study, mood disorders, anxiety, depression, and ADHD are significant and frequent problems for individuals with ASD.

One way that comorbid psychiatric disorders in children and adolescents with ASD have been identified is through the use of structured interview. The Kiddie Schedule for Affective Disorders and Schizophrenia for School-Age Children- Present and Lifetime version (KSADS-PL) has found rates of comorbid disorders as high as 74%/84% (current/lifetime) in adolescents with autism in a population-based sample (Mattila et al., 2010). Even higher rates of comorbid disorders are described in Joshi et al. (2010). The researchers used the Kiddie Schedule for Affective Disorders and Schizophrenia – Epidemiological Version (KSADS-E) and found 95% of children and adolescents with ASD had three or more comorbid psychiatric disorders. Individuals in the ASD group had significantly more comorbid disorders than a group of psychiatrically referred children and adolescents without ASD. Children and adolescents with ASD had higher rates of language disorders, multiple anxiety

disorders, and encopresis, while the non-ASD group had higher rates of substance use (Joshi et al., 2010). Finally, an earlier study used the KSADS-E to identify comorbid disorders in children, adolescents, and adults diagnosed with Asperger's Disorder (Ghaziuddin, Weidmer-Mikhail, & Ghaziuddin, 1998). Sixty-five percent of the participants had one or more comorbid disorders. Researchers found ADHD and depression were the most common comorbid disorders.

In addition to the KSADS, other structured interviews have been used to identify comorbid disorders in children and adolescents with ASD. In Arab children with ASD, 63% were diagnosed with one or more comorbid disorders by the Arabic version of the semistructured clinical interview for children and adolescents (Amr, Raddad, El-Mahesh, Bakr, Sallam, & Amin, 2012). Simonoff, Pickles, Charman, Chandler, Loucas, and Baird (2008) used the Child and Adolescent Psychiatric Assessment- parent version (CAPA) with children diagnosed with an ASD. Results of the study show that 70.8% of the children had at least one comorbid disorder. The most common disorders were social anxiety disorder (29.2%), ADHD (28.1%), and ODD (28.1%). Another clinical interview, the Dutch version of the Diagnostic Interview Schedule for Children IV-Parent (DISC-IV-P), has been used to investigate comorbidity in children with PDD-NOS (de Bruin, Ferdinand, Meester, de Nijs, & Verheij, 2007). The researchers found that 80.9% of children had at least one comorbid disorder, and 54.3% had two or more disorders. Behavior disorders (ADHD, ODD, and CD) were the most prevalent (61.7%) followed by anxiety disorders (simple phobias, Social Phobia, Separation Anxiety Disorder, Agoraphobia, OCD, and Generalized Anxiety Disorder) (55.3%). These high

rates of comorbidity demonstrated by multiple clinical interviews show that psychiatric disorders are a significant problem for adolescents with ASD.

Psychological problems in adolescents with ASDs have also been identified using behavioral checklists, including the Achenbach System of Empirically Based Assessment (ASEBA) Child Behavior Checklist (CBCL). A retrospective records study of high functioning adolescents with an ASD in Singapore using the ASEBA CBCL found that 86% of the adolescents in their sample had at least one of the CBCL syndrome scales in the clinical range (Ooi, Tan, Lim, Goh, & Sung, 2011). The most commonly reported syndrome scales were Social Problems (60.6%), Thought Problems (50.7%), Attention Problems (49.3%), and Withdrawn/Depressed (40.8%) (Ooi, Tan, Lim, Goh, & Sung, 2011, p372). The least reported syndrome scale was rule-breaking (12.7%). On the DSM-oriented scales, 72% had a scale in the clinical range. The most commonly reported DSM scales were Attention Deficit/Hyperactivity Problems (35.2%), Anxiety Problems (33.8%), and Affective Problems (31%) (Ooi, Tan, Lim, Goh, & Sung, 2011, p373). Kanne, Abbacchi, and Costantino (2009) used the ASEBA CBCL to investigate comorbidity and found 25% of the participants had elevations on the DSM-oriented scales indicating depression or anxiety, 25% had attention problems, 15% had oppositional defiant disorder, and 16% had conduct disorder. Use of the ASEBA has shown that individuals with ASD have elevated scores on the DSM and syndrome scales, which indicates the presence of significant psychological and behavioral problems in this population.

In addition to the CBCL, another checklist has been used to investigate the

presence of comorbid psychiatric disorders in children and adolescents with ASD. Autism Spectrum Disorders-Comorbid for Children (ASD-CC) was specifically created to investigate comorbid psychiatric symptoms in individuals with ASD. Researchers found that the worry/depressed, under-eating, over-eating, avoidant behavior, and repetitive behavior scales were significantly higher for children and adolescents with ASD than those without (Hess, Matson, & Dixon, 2010). Finding of significant problem behaviors with a measure specifically designed for use with individuals with ASD further demonstrates that comorbid psychiatric disorders and psychological problems occur in this population.

It is not clear if the comorbid behavioral and psychological problems that individuals with ASD exhibit are developmentally related to ASD. Usually only those individuals with higher functioning ASDs receive additional psychiatric diagnoses. Clinicians are generally reluctant to give additional diagnoses to individuals who have lower cognitive abilities, particularly those who are unable to provide reliable information about their psychological symptoms through interview or self-report scales (Tsai, 1996).

Even though comorbid psychological problems and conditions are frequently reported in cases of ASDs, there is a definite lack of research in the area. Most of the research consists of identification of comorbid psychiatric disorders in persons with ASD and reporting of the rates of each comorbid disorder, as seen in this section. Additionally, the population studied often only includes those diagnosed with Autistic Disorder rather than the full autistic spectrum, and the majority of studies conducted on

comorbid psychiatric conditions fail to make adequate comparisons with same-age peers and control or comparison groups (MacNeil, Lopes, & Minnes, 2009). The few studies that include comparison groups often use individuals with an intellectual disability as a comparison.

### Comorbidity and Intellectual Disability

When comorbidity is examined in ASD, individuals with intellectual disability are frequently used as a comparison group. These studies often involve comparing individuals that have ASD and intellectual disability to persons with intellectual disability. This is problematic since psychiatric problems in individuals with ASD and intellectual disability can be shown in atypical ways, such as self-injury, irritability, aggression, bizarre movements, and strange behavior (Bakken, et al., 2010).

Even with problems inherent in studying psychiatric disorders in this population, researchers have found that the occurrence of psychiatric disorders in adolescents and adults with autism and intellectual disability is 2.5 times higher than among individuals with intellectual disability without autism. Prevalence of psychosis, depression, anxiety, and OCD was significantly higher in adolescents and adults with autism than comparisons with intellectual disability, with depression being the most common disorder (Bakken, et al., 2010).

Findings are similar when comparing children and adolescents with autism to those with intellectual disability. Children with autism had significantly higher levels of overall psychopathology than children with intellectual disability. These children were

also more disruptive, self-absorbed, anxious, and had greater problems with communication problems and social relating (Bereton, Tonge, & Einfeld, 2006). Additionally, adolescents with autism and intellectual disability had significantly more symptoms of psychiatric disorders than adolescents with intellectual disability. Fifty percent of adolescents with autism had more than five clinically significant disorders, while 75% of adolescents with intellectual disability had one or no comorbid disorders (Bradley, Summers, Wood, & Bryson, 2004). Other studies have also found that individuals with autism have higher scores on stereotypes, mania, anxiety, and more episodes of psychiatric disorders when compared to those individuals with an intellectual disability (Bradley & Bolton, 2006; Hill & Furniss, 2006). These studies demonstrate that comorbid psychiatric disorders are a significant concern in persons with autism who are intellectually disabled; however, results may not apply to individuals who are higher functioning or those who have diagnoses of Asperger's Disorder or PDD-NOS.

### Comorbidity and High Functioning ASD

In addition to individuals with ASD and intellectual disability, comorbid psychiatric disorders have been studied in individuals with ASD that are “high functioning.” Researchers examined Diagnostic and Statistical Manual- Fourth Edition (DSM-IV) psychiatric diagnoses in children with ASD and emotional or behavioral problems. Witwer and Lecavalier (2010) found that children with an IQ above 70 and children with better verbal abilities were more likely to have symptoms of DSM-IV

disorders. The researchers concluded that individuals with a higher IQ and better language abilities are more able to report symptoms, and some DSM-IV criteria that depend on language are not applicable to individuals with limited verbal ability (Witwer & Lecavalier, 2010). Results of the study conducted by Sturm, Fernell, and Gillberg (2004) also demonstrate comorbid problems in high functioning children with ASD. The researchers found high rates of motor, attention, auditory perception, and tactile perception difficulties. These studies demonstrate that DSM-IV psychological disorders may be valid diagnoses in children and adolescents with average verbal ability and an IQ greater than 70, and that high functioning individuals with ASD may have functional problems.

Comparison between children and adolescents with Asperger's Disorder and high functioning autism has shown that comorbid disorders present similarly between groups. The only differences found were that children and adolescents with Asperger's Disorder had significantly more symptoms of Major Depressive Disorder and ADHD-Combined Type than individuals in the high functioning autism group. All other rates of disorders were similar between groups with high rates of ADHD and anxiety disorders (Mukaddes, Herguner, & Tanidir, 2010). Results of this study provide evidence that individuals with high functioning autism and individuals with Asperger's Disorder may be expected to present with similar comorbid psychiatric disorders.

### Risk Factors For Comorbid Disorders

A variety of risk factors for developing comorbid disorders in persons with ASD have been described in the literature; however, risk factors differ by study and there is no consensus on which factors are important. One analysis of risk factors for comorbid disorders in children with ASD found that living in a single parent household was associated with comorbid disruptive behavior disorders, such as ODD (Gadow, DeVincent, & Schneider, 2008). Hospitalizations of children for medical problems and complications during pregnancy were associated with anxiety and mood disorders. Additionally, family history of psychiatric disorders predicted all comorbid symptom categories except for ADHD-Inattentive Type and specific phobia. Treatment with psychotropic medications was associated with more severe ADHD, ODD, and depression. Even though these risk factors were predictive of comorbid disorders, all correlations were low, which indicates that further research needs to include a wider range of variables (Gadow, DeVincent, & Schneider, 2008).

There is debate about the role of cognitive ability as a risk factor. Some researchers have found that persons with “high functioning autism,” those with normal or higher levels of cognitive ability, have greater psychological problems (Pearson et al., 2006). However, other researchers have found that IQ is not predictive of psychiatric problems, but that presence of epilepsy is associated with psychiatric and behavioral disorders (Simonoff et al., 2008). Still other researchers have found that individuals with a greater number of autistic symptoms have a greater number of psychological problems (Kanne, Abbacchi, & Costantino, 2009). These conflicting



results indicate that the role of cognitive ability or “IQ” is not entirely clear, although greater numbers of autistic symptoms and epilepsy may be risk factors for comorbid psychiatric disorders.

Another possible risk factor for comorbid psychiatric disorders is later diagnosis of ASD. Levy et al. (2010) found that a later age of diagnosis of an ASD was associated with increased prevalence of psychiatric disorders. Additionally, co-occurrence of psychiatric disorders, neurological disorders, and other non-ASD diagnoses was associated with later age of first ASD diagnosis. Levy et al. (2010) hypothesize that the association between later age of ASD diagnosis and increased prevalence of other disorders may be due to a “masking effect” of the non-ASD conditions, mislabeling of ASD that co-occurs with other conditions, or it could be indicative of differences between isolated and complex ASD cases. On the other hand, it may be the autism condition itself that outweighs all other risk factors when it comes to developing psychiatric disorders (Simonoff et al., 2008).

Some factors have been found to not indicate a risk for developing comorbid psychiatric disorders. Adaptive behavior ability and family factors were not related to comorbid psychiatric disorders (Simonoff et al., 2008). Having a family history of ASD was also not predictive of comorbid disorders (Gadow, DeVincent, & Schneider, 2008). Male and female children and adolescents had a similar rate of psychiatric symptoms, which suggests that sex is not a risk factor (Worley & Matson, 2011). Finally, no significant difference in rates of comorbid disorders was found between individuals

diagnosed with high functioning autism and Asperger's Disorder, indicating ASD subtype is not a risk factor (Mukaddes, Herguner, & Tanidir, 2010).

### Psychological and Social Outcome

In terms of how well individuals with ASD who have comorbid psychiatric disorders do in the long run, studies that have been conducted have shown poor outcome and functioning among children, adolescents, and adults. One study found 10.8% of children and adolescents identified with ASD ended up at some point being hospitalized in psychiatric facilities (Mandell, 2008). However, rates were much higher in another study. Green, Gilchrist, Burton, and Cox (2000) reported that 40% of adolescents with Asperger's Disorder received inpatient psychiatric treatment. Other indications of poor outcome were also described. Only 50% of adolescents with Asperger's Disorder were independent in self-care activities, such as washing and brushing teeth, although independence increased with age. Additionally, none of the adolescents had a friendship of normal quality, and only one participant had ever had a girlfriend (Green, Gilchrist, Burton, & Cox, 2000). Results of these studies show that adolescents with ASD can have poor outcomes in multiple areas of their lives.

Psychiatric hospitalization represents a poor outcome for children and adolescents. Factors that made it more likely for children and adolescents to be hospitalized include engaging in self-injurious behaviors, being aggressive toward others, having a history of mood disorder or OCD, or already being prescribed psychiatric medications (Mandell, 2008). It has also been reported that 81% of children

and adolescents hospitalized at a psychiatric facility were admitted for aggressive acting out behaviors (Dekeyzer, 2004). Other factors that predicted hospitalization included the person being adopted, being African American, being older, and having parents or guardians without a college education and living without a spouse or partner (Mandell, 2008). Despite the evidence for these risk factors relating to poor outcome, Mandell (2008) concluded that the hospitalization of youth with ASD represented a failure of the community to provide adequate psychiatric treatment on an outpatient basis.

Poor outcome for individuals with ASD as children and adolescents continues into adulthood. Adults with ASD have poorer outcome and functioning than would be expected based on the individual's IQ (Marriage, Wolverton, & Marriage, 2009). A follow-up study on individuals with ASD who had been identified with autism as children found that the majority of individuals had not been educated in mainstream schools; most had attended special schools or were home schooled (Howlin, Goode, Hutton, & Rutter, 2004). As adults, these individuals had reading problems, and average age scores for reading were 10.54 years on accuracy and 8.70 years on comprehension. Additionally, only 5 participants (out of 68) went to college and one-third had jobs. Most of the jobs were low level and provided by family or occupational programs of the individuals' residential or day treatment programs (Howlin, Goode, Hutton, & Rutter, 2004). Howlin and her colleagues (2004) demonstrated that individuals with ASD continue to have significant problems into adulthood and many remain dependent on families or government programs to support them. These poor educational and employment outcomes show that the problems of children and adolescents continue into

adulthood.

Social outcome of individuals with ASD is also poor. Eaves and Ho (2008) found that only 21% of adolescents and young adults with ASDs were considered to have “good or very good” outcome. Only 2 individuals in their study were reported to work independently and 56% still lived at home. Furthermore, about 50% were diagnosed with an anxiety disorder with or without obsessive-compulsive features (including those meeting full criteria for OCD), as well as other psychiatric conditions. Another study found that only 26% of individuals with ASD had a friendship that involved sharing a range of interests and activities with another person, and only 1 (out of 68 participants) had married at the time of the follow-up (Howlin, Goode, Hutton, & Rutter, 2004). Similarly, results from recent investigations have shown that only 5 out of the 40 participants in one study had ever married (Farley, 2009). Continued symptoms of comorbid psychiatric disorders in adulthood and a lack of social relationships show that the difficulties of children and adolescents with ASD do not necessarily improve over time.

#### Awareness of Psychological Problems in Adolescents with ASD

One factor that may be related to outcome in adolescents with ASDs and comorbid psychiatric symptoms is awareness of psychological and behavior problems. However, there is a lack of research into the ability of adolescents with ASD to self-report problems. Most self-perception studies of individuals with ASD pertain to theory of mind and action monitoring (i.e., remembering which actions the participant

performed and the experimenter performed). Therefore, many of the studies in the literature that examine self-perceptions and autism are not relevant to perception of psychological problems and functioning.

There are a few studies, however, that are related to the subject of self-perception of problems in ASD, although they are limited in scope, only examine personality, or only focus on autism symptoms. Green, Gilchrist, Burton, and Cox (2000) used structured clinical interviews to compare social and psychiatric functioning in adolescents with Asperger's Disorder and adolescents with Conduct Disorder. The researchers interviewed both the adolescents and their parents. One of this study's findings was that only 25% of adolescents with Asperger's Disorder could give any description of their impairment due to ASD symptoms, 30% reported no difference from others, and only 30% were aware of why others saw them as different. Additionally, the interviewer judged only 15% of the adolescents with Asperger's Disorder to have a realistic perception of their problems (Green, Gilchrist, Burton, & Cox, 2000). While not the main focus of the study, these findings demonstrate a deficit in the adolescents' perception of their problems.

Another study examining a person's ability for awareness of problems used personality profiles and a measure of alexithymia. This study examined The Minnesota Multiphasic Personality Inventory-Second Edition (MMPI) and the Toronto Alexithymia Scale in college-age adults with ASD (Garcia, 2003; Ozonoff, Garcia, Clark, & Lainhart, 2005). Self-report personality scales were used to examine awareness of problems and study personality traits in adults with ASD. Researchers

found that adults with ASD had elevated scores on the Depression scale, Social Introversion scale, and Schizophrenic scale when compared to the control group. Ozonoff, Garcia, Clark, and Lainhart (2005) concluded that the elevations on these scales were consistent with what is known about the personality of persons with ASD. However, studies such as these do not specifically examine self-perceptions of psychological and functioning problems.

Even though individuals with psychological problems were not included, the study conducted by Johnson and his colleagues examined self-perceptions of children and adolescents with autism (Johnson, Filliter, & Murphy, 2009). Self-perceptions of empathy and autistic traits were studied by comparing responses of children and adolescents with and without ASD and their parents on the following rating scales: Systemizing Quotient, Empathy Quotient, and Autism Spectrum Quotient. Although the comparison group was considered “typically developing” peers without ASD, both the comparison individual and his/her parent were asked to complete the autism scale that measured “autistic traits.” As expected, researchers found that both the individual and parent in the ASD group reported that the youth with ASD had significantly more autistic symptoms than control group youth. More importantly, the children and adolescents with ASD endorsed significantly fewer autistic symptoms than on the parent-report. Additionally, the children and adolescents with ASD had higher self-report of empathy than parent-reported empathy. On the other hand, there was no difference between the control group youth and their parents in terms of empathy ratings. This study suggests that typically developing youth were able to self-perceive

their ability for empathy, whereas youth with an ASD were not as capable of this level of self-perception (at least not when compared to parent reports).

### Self and Other Reports of Psychological Problems

In order to compare self- and parent-perceptions of adolescents with ASD, it is necessary to compare ratings of multiple informants. However, there are few studies that examine cross-informant reports in children and adolescents with ASD. Among typically developing children, correlation between informant reports has been examined. Achenbach, McConaughy, and Howell (1987) conducted a meta-analysis on cross-informant ratings of emotional and behavior problems. The researchers found that informants playing a similar role for the child (pairs of parents or pairs of teachers) had correlation of  $r = 0.60$  between their ratings. This relatively high correlation is replicated in the multigroup confirmatory factor analysis conducted by Konold, Walthall, and Pianta (2004). The factor analysis demonstrated that mothers' and fathers' ratings were not significantly different, and teacher ratings were not significantly different from parent ratings. Additionally, results of these studies indicate that gender of the child and clinical versus nonclinical status of the youth did not affect correlations. Ratings were also consistent over time (Achenbach, McConaughy, & Howell, 1987; Konold, Walthall, & Pianta, 2004). These studies show that similar information can be obtained from persons who play similar roles in a child's life.

On the other hand, the relationship between self- and parent-report is less clear. Achenbach, McConaughy, and Howell (1987) found a correlation of  $r = 0.25$  between

self- and parent-report of emotional and behavior problems. A more recent meta-analysis had similar findings with self- and parent-report of social problems having a correlation of  $r = 0.20$  (Renk & Phares, 2004). The researchers conclude that different informants do not typically provide the same information so it is necessary to use multiple informants for a complete assessment of a child (Achenbach, McConaughy, & Howell, 1987; Renk & Phares, 2004).

The low correlations found in meta-analyses of cross-informant ratings are not reproduced in the ASEBA manual (Achenbach & Recorla, 2001). The ASEBA is reported to have self- and parent-report correlations that range from  $r = 0.37$  to  $0.56$  with a mean of  $r = 0.48$  for the empirically based scales. A reason for this disparity may be due to correlations between informants varying by measure since some measures and questionnaires have been found to have higher correlations between informants than others (Mazefsky, Kao, & Oswald, 2011). Regardless of the reason for the difference between correlations, the researchers agree that obtaining information from multiple informants, including the child, is best practice (Achenbach, McConaughy, & Howell, 1987; Mazefsky, Kao, & Oswald, 2011; Renk & Phares, 2004).

The few studies that have examined difference between self- and parent-report in children and adolescents with ASD have provided some evidence of the validity of self-report measures in this population. Blakeley-Smith, Reaven, Ridge, and Hepburn (2012) found that parent-reported symptoms of anxiety in children with ASD were higher than self-reported symptoms; however, children and their parents had “fair to strong” agreement on ratings of anxiety symptoms. Additionally, children with better



verbal ability had better agreement with their parents on anxiety symptoms. Another study found that after cognitive-behavioral therapy (CBT) for anxiety disorders in children with ASD, both self- and parent-reports showed a decrease in symptoms of anxiety (Chalfant, Rapee, & Carroll, 2007). These studies suggest that the children with ASD are able to report their symptoms of anxiety and improvement after treatment.

Even though children and adolescents with ASD may be able to accurately self-report, caution in the interpretation of their responses has been advocated by some researchers (Mazefsky, Kao, & Oswald, 2011). The researchers compared results of a clinical interview with parents of children and adolescents with ASD to self-report checklists of anxiety and depression. Results showed that even when the parent interview suggested that the youth had significant psychological problems, the self-reports of individuals did not indicate clinical problems. While caution in interpretation may be warranted, this study compared parent clinical interview to self-report checklist rather than comparing parent- and self-rating forms of the same assessment and did not include a control group for comparison.

Overall, the evidence for comparison of multi-informant ratings suggests that correlations between parent- and self-report may be low in some cases. However, the correlation between parent- and self-report on the ASEBA is reported to be medium and preliminary evidence suggests children and adolescents with ASD are able to report psychological symptoms in a manner similar to parent report.

### Studies Examining Psychopathology and Everyday Functioning

There are two studies that have examined psychopathology and functioning in adolescents with ASD in a manner similar to the current study. Hurtig et al. (2009) administered the 1991 version of the ASEBA Child Behavior Checklist (CBCL), Youth Self-Report (YSR), and Teacher Report Form (TRF) to adolescents with high functioning autism or Asperger's Disorder and to controls. The purpose was to examine a broad range of psychiatric symptoms in higher functioning adolescents on the autism spectrum as reported by multiple informants. The researchers believed that inclusion of children with lower than average intelligence in other studies may have increased psychiatric problems in those samples due to children with intellectual disability having higher rates of comorbid psychiatric disorders (Hurtig et al., 2009). Results of the study show that significantly more adolescents with ASD had clinically significant scores on the YSR Total score, Internalizing, Withdrawn/Depressed, Anxious/Depressed, Social Problems, Thought Problems, and Attention Problems than adolescents in the control group. Additionally, parents of children with ASD reported significantly more problems on the CBCL on all scales than parents of control group adolescents. There were no significant differences between gender, diagnosis, or recruitment group, except that females with ASD endorsed more thought problems than males with ASD, and males in the control group reported more delinquency problems than control group females. Comparison of informant responses revealed that parent and adolescent scores in the ASD group had a strong positive correlation on Somatic Complaints, Social Problems, Delinquent Behavior, Aggressive Behavior, and Externalizing. However, adolescents

with ASD reported more problems on the Anxious/Depressed, Thought Problems, and Total scales than parents reported, and control group adolescents reported more problems on all scales than their parents reported. The researchers concluded that adolescents with ASD and their parents have better agreement on social and externalizing problems than on anxious and depressive symptoms (Hurtig et al., 2009). This study demonstrates that the perceptions of adolescents with ASD can be similar to parent perceptions of psychological problems in some areas and that adolescents with ASD can over-report problems when compared to parents.

The second study similar to the current one used the KSADS-PL to investigate comorbid psychiatric symptoms and the Children's Global Assessment Scale (CGAS) to assess functioning (Mattilla et al., 2010). CGAS scores range from 0 to 100 with higher scores representing better everyday functioning and scores below 70 indicating psychiatric disturbance and limited functioning (Mattilla et al., 2010). The study sample consisted of adolescents with high functioning autism and Asperger's Disorder in Finland from a community-based study and from a clinic-based study. The researchers found 74% of adolescents had a current comorbid disorder and 84% had previously had one in their lifetime. The most common disorders were behavioral (ADHD, ODD, and CD), anxiety, and tic disorders. The mean current level of functioning was 62 out of 100 on the CGAS, which indicated limited functioning. Current anxiety, behavioral, or mood disorders were associated with lower functioning CGAS scores. Current major depressive disorder, ODD, or having two comorbid disorders also decreased functioning. This study demonstrates that psychiatric symptoms may be associated with

decreased functioning and that many adolescents with an ASD have significant psychological problems.

While these studies investigate adolescent and parent perceptions of psychological problems and functioning of adolescents with ASD, they have several shortcomings. Hurtig et al. (2009) included comparison of parent and adolescent report of psychological symptoms; however, the main focus of the article was comparison of the ASD group to the control group. Mattilla et al. (2010) examined the functioning of adolescents with ASD; however, a control group was not included and the adolescents' perception of their functioning was not assessed. Therefore, further research is needed in order to examine the perceptions of psychological problems and functioning of adolescents with ASD.

#### Purpose of the Study

Comorbid psychiatric disorders are an ongoing issue for many adolescents with ASD. However, these individuals are often unaware of the seriousness of their psychological symptoms and deficits in functioning. Previous research has examined some aspects of self-perception in individuals with ASD; however, it is limited in that Mattilla et al. (2010) did not ask adolescents to rate their own functioning, and Hurtig et al. (2009) focused on comparing adolescents with ASD to typically developing peers rather than on the differences between adolescent- and parent-report. No study examined parent- and adolescent-reported problems on the ASEBA and on a scale of current and predicted future functioning.

The current study compares parent and child reports of everyday functioning and psychological problems in adolescents with ASD. Previous research on adolescents with ASD has shown that these individuals often do not have an accurate view of themselves (Johnson, Filliter, & Murphy, 2009). Hurtig et al. (2009) was the only study found to examine parent- and self-report on the ASEBA for adolescents with ASD. This study continues that line of research and examines reports of psychological problems and everyday functioning in a population of adolescents with ASD who have been treated for psychiatric disorders.

### Research Hypotheses and Questions

The following hypotheses and research questions were generated by examining previous research on adolescents with ASDs using the ASEBA.

#### Hypotheses

H1. Scale scores from the ASEBA YSR self-report of participants with ASD will be significantly lower than scale scores on the ASEBA CBCL parent-report on the following composite scale and subscales: Total, Rule-Breaking Behavior, Attention Problems, and Aggressive Behavior.

H2. The composite Externalizing score on the ASEBA YSR self-report of participants with ASD will be significantly higher than the composite Internalizing score on the ASEBA YSR self-report.

H3. The average score for current functioning on the Rating of Functioning self-

report of participants with ASD will be significantly higher than the average score for current functioning on the Rating of Functioning parent-report.

H4. The average score for future functioning (in 6 months) on the Rating of Functioning self-report of participants with ASD will be significantly higher than the average score for future functioning (in 6 months) on the Rating of Functioning parent-report.

H5. The average score for future functioning (in 6 months) on the Rating of Functioning self-report of participants with ASD will be significantly higher than the average score for current functioning on the Rating of Functioning self-report.

H6. The parent-report ASEBA CBCL Total score for participants with ASD will be significantly positively correlated with difference scores between participants' self-report on the Rating of Functioning scale and the parent-report on the same scale.

(Caveat: This hypothesis may need to be removed since it depends on a difference score and the parent score on the ASEBA likely has a correlation with the parent score on the Rating of Functioning since they are rated by the same person.)

### Research Questions

The following research questions were generated to further investigate differences between self- and parent-report. Additionally, they were intended to examine differences between adolescents with ASD and adolescents in the control group.

1. What is the difference between parent- and self-report scales on the ASEBA

CBCL and YSR for participants with ASD and participants in the control group and what are any differences between groups?

2. What is the difference in the average score between self- and parent-reports on the Rating of Functioning for participants with ASD and participants in the control group and what are any differences between groups?

## CHAPTER II

### METHODS

#### Recruitment

The primary investigator (PI) and faculty supervisor met with directors of the psychiatric hospital and child and adolescent psychiatric clinic to discuss the study and obtain approval to recruit participants at their sites. This study was approved by the Institutional Review Board of the University of Utah and the University of Utah Health Center Department of Psychiatry. The PI made weekly contact by email, phone, or visits to meet with staff members who were able to help with recruiting participants. Informational flyers were left with clinic staff to distribute to their clients and were placed around the waiting room in the clinic. The flyers contained information about participant requirements and the PI's contact information (see Appendix A for flyers).

Parents of potential participants from the psychiatric hospital were contacted and given information to determine whether or not they and their child were interested in the study. Potential participants from the child and adolescent psychiatric clinic received informational flyers at the clinic. If the parent and adolescent agreed to participate in the study, then an appointment was made to review the study and administer the assessments. This meeting took place at the adolescent's home or at the psychiatric



hospital, whichever was more convenient for the parent and adolescent.

Control group participants were recruited through contacts at the university and with flyers placed around the local urban area. Parents who saw flyers called the PI to receive more information and set up a meeting. Recruitment for control group participants was initially difficult so \$10 was offered to the adolescent to compensate them for their time. Participants with an ASD did not receive monetary compensation.

A control group was included in this study in order to provide a comparison to the adolescents with ASD. Without a control group, any findings could be argued to be due to the participants being adolescents and underreporting behavior because of their age. It could also be said that all adolescents have a different report of problems than their parent. Therefore, a control group was included so that the ASD group could be compared to typically developing adolescents in order to determine which findings were due to ASD and comorbid psychiatric disorders.

### Participants

Participants were males between the ages of 11 and 18 who were living with a biological parent or a guardian who knew the adolescent's history since birth. Twenty-one adolescents with ASD (Autistic Disorder, Asperger's Disorder, or PDD-NOS) were recruited from the inpatient and outpatient adolescent units at a university-based psychiatric hospital, and 5 adolescents with ASD were recruited from an outpatient child and adolescent psychiatric clinic. Additionally, 26 control group participants were recruited through contacts at the university and fliers placed around the local

community.

All adolescents with ASD were diagnosed with Autistic Disorder, Asperger's Disorder, or PDD-NOS by a psychiatrist or psychologist, and all had previously completed the Autism Diagnostic Observation Schedule (ADOS) (Lord et al., 2000) as part of the standard procedures at the outpatient clinic and psychiatric hospital. Every adolescent with ASD had previously received outpatient psychiatric treatment. Additionally, all adolescents with ASD were diagnosed, by a psychiatrist or psychologist, with a comorbid psychiatric disorder other than a developmental or learning disorder (e.g., mood disorder, anxiety, ADHD) using either the DSM-IV-TR (American Psychiatric Association, 2000) or ICD-10 (World Health Organization, 1992). Participants in the control group were required to have no current or past history of psychiatric disorders, psychiatric treatment, psychiatric medication use, or concerns about ASD.

All participants had a standard score of 85 or higher on the Wechsler Abbreviated Scales of Intelligence (WASI) and a reading score of 5<sup>th</sup> grade or higher on the Word Reading subtest of the Wide Range Achievement Test 4 (WRAT4). This reading ability cut-off as well as a measured IQ of 85 helped ensure that the participants were able to read and understand items on the self-report measures.

#### Data Collection Procedures

At the meeting with the parent and adolescent, the study was reviewed and informed consent was obtained (see Appendixes B and C for consent forms). All

participants were administered the WASI and the WRAT4 to ensure that they met study criteria of at least a 5<sup>th</sup>-grade reading level and an IQ of 85 or higher. The two-subtest version of the WASI was administered first, followed by the Word Reading subtest of the WRAT4. While the adolescent completed these assessments, his parent filled out the demographic questionnaire, the ASEBA CBCL, and Rating of Functioning parent report. After adolescents completed the WASI and WRAT4, they were given the ASEBA YSR and the Rating of Functioning self-report form to complete. During this time, the parent completed the developmental history interview with the PI. Rating forms were checked for completeness and participants were asked to fill in any missing items. Following the study, a summary of the results was mailed to the parent. All identifying information was removed as results were entered into a database for analysis. These procedures were followed for participants in both the ASD group and control group.

### Measures

The *Achenbach System for Empirically Based Assessment* (ASEBA) is an assessment system that consists of a variety of behavioral checklists designed to assess behavior and psychological problems in children and adolescents from the perspective of different raters. The two checklists used in this study were the Child Behavior Checklist for Ages 6-18 (CBCL), which is the parent report, and the Youth Self Report/11-18 (YSR) (Achenbach & Rescorla, 2001). The CBCL includes 113 items, and the YSR includes 112 items. Items consist of a statement, and the informant is

instructed to rate how true the statement is of the adolescent. All items are rated on a scale of 0-2 (0 = Not True, 1 = Somewhat or Sometimes True, and 2 = Very True or Often True).

When the ASEBA is scored, *T*-scores (mean = 50, standard deviation = 10) are generated for all scales. The scales include empirically based scales and DSM-oriented scales. Empirically based scales include Anxious/Depressed, Withdrawn/Depressed, Somatic Complaints, Social Problem, Thought Problems, Attention Problems, Rule-Breaking Behavior, and Aggressive Behavior. DSM scales include Affective Problems, Anxiety Problems, Somatic Problems, Attention Deficit/Hyperactivity Problems, Oppositional Defiant Problems, and Conduct Problem (Achenbach & Rescorla, 2001). These scales are based on factor analyses coordinated across the forms. The manual for the ASEBA labels *T*-scores of 64 and lower as in the normal range. *T*-scores of 65-69 are described as being in the borderline clinical range; they are high enough to be of concern, although not high enough to be clinically significant. Finally, *T*-scores of 70 and higher are labeled as clinical, since the person who completed the rating reported enough problems to be of a clinical concern (Achenbach & Rescorla, 2001).

The ASEBA has been demonstrated to be a reliable measure with good cross-informant agreement. The mean test-retest reliability of the empirically based scales is  $r = 0.90$  for the CBCL and  $r = 0.82$  for the YSR (Achenbach & Rescorla, 2001). Cross-informant agreement on the empirically based scales shows high correlations between mothers and fathers and medium correlations between parents and children. Correlations between mother and father ratings for the empirically based scales ranged

from  $r = 0.65$  to  $r = 0.85$ , with a mean of  $r = 0.76$ . Correlations between parent and child rating on the empirically based scales ranged from  $r = 0.37$  to  $r = 0.56$ , with a mean of  $r = 0.48$  (Achenbach & Rescorla, 2001). These correlations demonstrate that the empirically based scales of the ASEBA are reliable measures of adolescent psychological and behavior problems with good agreement between informants.

The ASEBA has also been shown to be a valid measure of psychological and behavior problems. Multiple regression analysis demonstrates that all scale scores were able to discriminate significantly between clinically referred and nonreferred children (Achenbach & Rescorla, 2001). When all scales were combined, the CBCL correctly classified 87% of children, and the YSR correctly classified 80% of children as referred or nonreferred. There are also high correlations between the ASEBA and other behavior scales. The Attention Problems scale has a correlation of  $r = 0.77$  with the ADHD Index of the parent form of the Conners Rating Scale, and the Aggressive Behavior scale has a correlation of  $r = 0.79$  with the Oppositional scale on the parent form of the Conners Rating Scale. Correlations with scales on the Behavior Assessment System for Children (BASC) ranged from  $r = 0.38$  to  $r = 0.89$  although most correlations were greater than 0.50 (Achenbach & Rescorla, 2001). The ability to correctly classify clinically referred children and the high correlations with other behavior rating scales demonstrate that the ASEBA is a valid measure of psychological and behavioral problems.

In addition to psychometric investigations in samples of normal and clinically referred children, the CBCL has also been used with children with ASD. Hurtig et al. (2009) examined multi-informant ratings using the CBCL of adolescents with high

functioning autism and a control group. They found that informants reported more psychiatric symptoms in the adolescents with autism. The CBCL has also been used to differentiate between children and adolescents with autism and those without (Mazefsky, Anderson, Conner, & Minshew, 2010). These researchers found that the Attention, Social, and Thought Problems scales had the most difference between the children with autism and the controls. Researchers have even used the CBCL to construct profiles of children and adolescents with autism in Singapore (Ooi, Rescorla, Ang, Woo, & Fung, 2010). These varied uses of the CBCL in populations with ASD demonstrate that it is a suitable instrument to use when investigating psychiatric problems in adolescents with ASD.

The *Rating of Functioning* is an investigator-generated measure created for this study (see Appendix D). It is intended to assess self- and parent-report of everyday functioning in the areas of school, home, and social functioning. Some items on this measure and the scale used for rating items were adapted from a questionnaire intended to assess the work performance of TBI survivors (Sossikian, 1999). Wording in the items from the questionnaire used by Sossikian was adjusted to take into account the age of the participants and the fact that most of them were in school. Items were also adapted from the Social Skills Improvement System (Gresham & Elliott, 2008) and the Behavior Assessment System for Children- Second Edition (Reynolds & Kamphaus, 2004). Wording had to be adjusted to make questions appropriate for the rater and to make them fit the other items in the Rating of Functioning. Additional items were created by the PI to assess problems that adolescents with ASD may experience.

The Rating of Functioning contains 31 items, two open-ended questions, and has adolescent and parent versions. Both versions are identical except pronouns are changed to accommodate the different raters. The measure contains items to rate potential problems in the areas of school, home, and social functioning. Each item consists of a statement about an action or activity at which an adolescent may do poorly or excel. The informant is instructed to rate how often the statement happens for the adolescent. Informants give two ratings for each item. The first rating represents the adolescent's current behavior (within the past 2 weeks), and the second rating represents how the informant thinks the child will perform on the item in 6 months. Items are rated on a Likert-type scale for frequency of occurrence from "rarely" to "very often". The scale is scored as follows: 1 = Rarely, 2 = Infrequently, 3 = Sometimes, 4 = Often, and 5 = Very Often. Most items are scored so that a score of 1 or "rarely" indicates a problem for the participant. A few items are reverse scored so that a rating of 5 or "very often" indicates that the item is a problem for the participant. Reverse scored items include those numbered 2, 23, 29, 30, 31.

The *Parent Interview* is a questionnaire generated by the PI for this study and consists of a questionnaire a parent filled out and the researcher completed during the structured interview (see Appendix E). It was intended to gather information about all adolescent participants in the ASD and control groups. The Parent Interview asks parents to provide information about family history of psychiatric disorders; the adolescent's developmental, educational, treatment, and psychiatric history; and the adolescent's behavior. The questionnaire portion contains items taken from the parent

questionnaire in Gabrielsen (2009) and items created by the PI.

The interview portion was created by adapting and combining questions from several structured interviews. One source of questions is the Kiddie Schedule for Affective Disorders and Schizophrenia for School-Age Children- Present and Lifetime version (KSADS-PL) (Kaufman, Birmaher, Brent, Rao, & Ryan, 1996). It is a semi-structured interview for assessing and obtaining information about current and past psychiatric disorders in children and adolescents. Another source of questions is from a structured interview used by Farley (2009), which was adapted from Howlin, Goode, Hutton, and Rutter (2004). This interview was intended to assess outcome for adults with ASDs. Finally, the coding sheet used by Dekeyzer (2004) to categorize psychiatric information of adolescents with ASDs was examined to ensure that all areas of interest were covered. Questions from these three sources were examined and combined to create a parent questionnaire and interview that gathered information in a variety of areas. Since the same Parent Interview form was used for both the ASD and control groups, questions were addressed to the parents in a way that was appropriate given the adolescent's ASD status (i.e., parents in the ASD group were not asked if their child had ASD; instead, they were asked which specific ASD diagnosis the child had and who first gave the diagnosis).

The *Wechsler Abbreviated Scale of Intelligence* (WASI) is a brief measure of cognitive ability. It is individually administered and can be used with individuals ages 6 to 69. The WASI consists of four subtests including Vocabulary, Block Design, Similarities, and Matrix Reasoning. Administering all four subtests yields Verbal,



Performance, and Full Scale scores. If the two-subtest form is administered, then the Vocabulary and Matrix Reasoning subtests are given, which yields only a Full Scale score. Subtests of the WASI are similar to those in the WISC-III and WAIS-III and are those that have the highest loadings on  $g$  (Psychological Corporation, 1999). The two-subtest form is described as being useful as a screening instrument to obtain a general summary of an individual's cognitive functioning (Psychological Corporation, 1999).

The standardization sample of the WASI included 2,245 children and adults who were selected to be representative of the sex, race/ethnicity, educational level, and geographic regions of the United States. The manual for the WASI states that split half reliability methods were used (Psychological Corporation, 1999). For children, the average reliability coefficients of the subtests ranged from .87 to .92. Additionally, the average reliability coefficients for the Full Scale IQ-4 (4 subtest) ranged from .95 to .97 and the average Full Scale IQ-2 (2 subtest) coefficients ranged from .92 to .95 for children. In the adult standardization sample, the average reliability coefficients ranged from .92 to .94. The average reliability coefficients for the Full Scale IQ-4 ranged from .96 to .98 and average coefficients ranged from .93 to .98 for the Full Scale IQ-2 (Psychological Corporation). These reliability coefficients indicate that the WASI is a reliable measure of general cognitive ability.

The WASI was designed to have content validity by ensuring that WASI subtests were similar to their counterparts on the WISC-III and WAIS-III (Psychological Corporation, 1999). Additionally, concurrent validity was shown since the correlation between the WASI Full Scale IQ-4 and WISC-III was .87, and the

correlation was .81 between the WASI Full Scale IQ-2 and the WISC-III Full Scale IQ. Concurrent validity was also shown for adults. The correlation between the WASI Full Scale IQ-4 and the WAIS-III Full Scale IQ was .92 and was .87 between the WASI Full Scale IQ-2 and the WAIS-III Full Scale IQ (Psychological Corporation). These correlation coefficients indicate that a large portion of variance in IQ scores is accounted for by the WASI and it is a valid estimate of an individual's general cognitive ability. Independent studies also support the utility of the WASI. Raggio, Scattone, and May (2010) found that WASI was a more stable measure of intelligence for children with ADHD than the Kaufman Brief Intelligence Test (KBIT-2). Another study found that the WASI measures the same constructs as the Wide Range Intelligence Test (WRIT) and global test scores did not meaningfully differ between the two tests (Canivez, Konold, Collins, & Wilson, 2009).

The *Wide Range Achievement Test 4* (WRAT4) is a norm-referenced test of achievement that includes age- and grade-based norms. It is intended to be a quick assessment of the fundamental academic skills of reading, writing, and arithmetic (Wilkinson & Robertson, 2006). There are four subtests on the WRAT4 including Word Reading, Sentence Comprehension, Spelling, and Math Computation. There are multiple tests of reliability and validity presented in the manual that provide evidence for the WRAT4's use. Only the coefficients for the blue form (the green form is an alternate form) will be stated since coefficients are virtually identical for both forms. The median internal consistency reliability coefficients were .92 for word reading, .93 for sentence comprehension, .91 for spelling, and .89 for math computation. The

alternate form immediate retest reliability median coefficients ranged from .82 to .90 for the subtests (Wilkinson & Robertson, 2006). These reliability coefficients provide evidence that the WRAT4 is a reliable test of academic ability.

Multiple types of evidence for the validity of the WRAT4 are presented in its manual. Seventy-seven percent of the items on the WRAT4 were drawn from the WRAT3, and items received extensive statistical analysis on the WRAT3 (Wilkinson & Robertson, 2006). The Word Reading subtest of the WRAT4 had moderate to moderately high correlation with reading subtests on other academic measures. Correlation with the WIAT-II Word Reading was .71, .66 with the Woodcock-Johnson III Basic Reading subtest, and .76 with the KTEA-II Comprehensive Letter/Word Recognition subtest (Wilkinson & Robertson, 2006). The median correlation of the Sentence Comprehension subtest with other reading comprehension subtests was .60, and the median correlation of the Spelling subtest with other measures of spelling was .77. Finally, the correlation of the Math Computation subtest with other math subtests was .74. These correlations with other academic measures indicate that the WRAT4 is likely a valid measure of academic ability.

Additionally, independent studies have found evidence to support use of the WRAT4. Vance and Fuller (1995) found that the WRAT3 had significant positive correlations with the WISC-III when used with children referred for special education services. Another study compared scores on the WRAT3 and the WIAT from children classified as learning disabled who received special education resource services (Smith & Smith, 1998). These researchers found that there were significant correlations on the

two tests and mean subtest scores were not significantly different between corresponding subtests. Although these independent studies were conducted with the WRAT3, they provide evidence for use of the WRAT4 to measure academic ability.

### Data Analysis

#### Comparison Between and Within Groups

In order to complete the analysis, data from all autism spectrum disorders (Autistic Disorder, Asperger's Disorder, and PDD-NOS) were analyzed together in one ASD group. Additionally, adolescents recruited from the outpatient clinic and adolescents from the psychiatric hospital were analyzed as one group. Only 8 participants had never had inpatient treatment at a psychiatric hospital, and only 3 of those 8 were recruited through the outpatient clinic. There were too few participants recruited from the outpatient clinic and too few adolescents who had never had inpatient psychiatric treatment to form groups based on those factors for analysis. Thus all adolescents with ASD were analyzed together, regardless the referral source and previous inpatient treatment.

Data analysis was carried out using the SPSS computer program, and the primary methods of analysis used to examine the data were paired samples *t*-test and repeated measures analysis of variance (ANOVA). Paired samples *t*-test was used to examine differences between parent and adolescent ratings within the ASD group and within the control group. It was necessary to use a paired samples *t*-test due to the characteristics of the data. Each parent and adolescent's scores are not independent

since they have a familial relationship. A paired-samples *t*-test matches each parent and adolescent's score on a measure to account for the correlation.

Repeated measures ANOVA (also called within-subjects ANOVA) was used rather than a standard two-way ANOVA since it also accounts for correlation between parent and adolescent. A typical two-way ANOVA is not appropriate because the assumption of independence of groups would be violated. The repeated measures ANOVA is suitable since the behavior of the adolescents is being measured twice (once by their parents and once by themselves). Comparisons between adolescents in the ASD group and the control group were also made. These two groups are independent so the analysis was a repeated measures ANOVA with a between-subjects factor. Finally, Pearson correlation was used to examine the relation between the difference between parent and adolescent report on the Rating of Functioning and parent CBCL Total Score.

### Definitions

Statistical significance. For all statistical tests, significance was determined at the 0.05 level ( $p = 0.05$ ).

Self-awareness/ Awareness. Awareness of problems was defined by comparing parent and adolescent reports. If adolescent reports were not significantly different than parent reports, then the adolescents were considered to be aware of their problem behaviors. If adolescent reports were significantly lower than parent reports, then the

adolescents were considered to be unaware of problems. It is possible parents were not aware of problems; however, this is how awareness of problems was defined.

Magnitude of effect size. Cohen (1988) suggests a possible interpretation of effect sizes where  $d = 0.2$  represents a small effect,  $d = 0.5$  is a medium effect, and  $d = 0.8$  represents a large effect.

### Effect Size

Hedge's  $d$ . Although some studies use Cohen's  $d$  to report an effect size, in the current study, the effect size  $g$  with a conversion to  $d$  was used for the effect size of  $t$ -tests (Hedges & Olkin, 1985). Hedges and Olkin use the effect size  $g$  developed by Glass. It is the difference between control and treatment group expressed in standard deviation units,  $g$ . In order to calculate an effect size for the paired samples  $t$ -test, which is a within-subject design, the same formula that is commonly used for between-subjects designs was used except the pooled standard deviation was replaced by  $s_D$ , which is the standard deviation of the difference between observations. One group's mean was subtracted from the other group's mean. This difference was then divided by the standard deviation of difference between groups, which is shown in the following formula:

$$g = \frac{(M_1 - M_2)}{s_D} ,$$

(Hedges & Olkin, 1985). The standard formula used to calculate effect size for

between-subjects designs cannot be used since it assumes independence of groups.

In studies with small sample sizes, the  $g$  statistic has a tendency to overestimate effect size. This is especially true with sample sizes less than 20 (Hedges & Olkin, 1985). With large sample sizes,  $d$  and  $g$  are similar, but with small sample sizes, the difference can be significant. In order to correct this bias, the equation for within-subjects designs was used to convert  $g$  to  $d$ :

$$d = (1 - \frac{3}{4(N-1)-1})g ,$$

where  $N$  is the total sample size ( $n_E + n_C$ ) or number of pairs in a paired samples  $t$ -test (Hedges, 1981; Hedges & Olkin, 1985). Since all groups were equal, the correction factor used to correct the  $g$  obtained from all paired-samples  $t$ -tests was the same (0.969697). Thus, the formula for this study becomes:

$$d = (0.969697)g .$$

Partial eta-squared. For repeated measures ANOVA, partial eta-squared (Partial  $\eta^2$ ) was calculated to estimate the effect sizes of the different factors of the ANOVA. Partial eta-squared represents the amount of variance that can be contributed to a factor if all of the other factors are excluded from the variance, and it ranges from 0 to 1 (Pierce, Block, & Aguinis, 2004). It can be interpreted as representing the percent of variance attributable to the factor when all other factors are excluded. Partial eta-

squared shows the effect of each factor in isolation as if it were examined with a one-way ANOVA. Partial eta-squared differs from eta-squared in that eta-squared represents the portion of total variation attributable to a factor, including all factors in the analysis (Pierce, Block, & Aguinis, 2004). Partial eta-squared is usually greater than eta-squared, although they are equal when the analysis only has one factor. Eta-squared and partial eta-squared are calculated as follows:

$$\eta^2 = \frac{SS_{Factor}}{SS_{Total}},$$

$$Partial \eta^2 = \frac{SS_{Factor}}{(SS_{Factor} + SS_{Error})},$$

(Pierce, Block, & Aguinis, 2004).



## CHAPTER III

### RESULTS

#### Characteristics of Participants

##### Demographics

In total, 52 pairs of adolescents and their parents participated in the study. There were 26 adolescents in the ASD group and 26 in the control group. The ASD group included 21 adolescents identified as Caucasian, 3 as Hispanic, 1 as Asian, and 1 as Caucasian/Asian (ethnicity of adolescents was parent-reported). All adolescents in the control group were identified as Caucasian. Seven adolescents in the ASD group were diagnosed with Autistic Disorder, 12 with Asperger's Disorder, and 7 with PDD-NOS. Nineteen of the adolescents with ASD currently or previously received special education services, and 8 had currently or previously been on a 504 plan. Two control group adolescents had previously received special education speech services in early elementary school, and none had ever been on a 504 plan.

The ages of participants were similar between the ASD and control groups (see Table 2). Adolescents in the ASD group ranged from 11 years, 0 months to 18 years, 9 months, with a mean age of 14 years, 9 months and standard deviation of 1 year, 11.5 months. Adolescents in the control group ranged from 11 years, 0 months to 18 years,

Table 2

*General Participant Characteristics*

		Age (in years)	WASI Full Scale	WRAT4 Word Reading (Grade Level)	Parent-Reported Grade Point Average
ASD	<b>Mean</b>	<b>14.77</b>	<b>105.23</b>	<b>10.43</b>	<b>2.98</b>
	<i>Standard Deviation</i>	<i>1.96</i>	<i>8.93</i>	<i>2.44</i>	<i>0.84</i>
Autistic Disorder	<b>Mean</b>	<b>14.14</b>	<b>104.86</b>	<b>9.59</b>	<b>2.32</b>
	<i>Standard Deviation</i>	<i>2.49</i>	<i>6.28</i>	<i>2.73</i>	<i>0.35</i>
Asperger's Disorder	<b>Mean</b>	<b>15.10</b>	<b>110.33</b>	<b>10.89</b>	<b>3.00</b>
	<i>Standard Deviation</i>	<i>1.76</i>	<i>7.48</i>	<i>2.54</i>	<i>1.00</i>
PDD-NOS	<b>Mean</b>	<b>14.81</b>	<b>96.86</b>	<b>10.47</b>	<b>3.50</b>
	<i>Standard Deviation</i>	<i>1.84</i>	<i>7.52</i>	<i>2.07</i>	<i>0.33</i>
Control	<b>Mean</b>	<b>13.90</b>	<b>110.92</b>	<b>9.80</b>	<b>3.55</b>
	<i>Standard Deviation</i>	<i>2.17</i>	<i>8.33</i>	<i>2.51</i>	<i>0.55</i>

9 months, with a mean age of 13 years, 11 months and a standard deviation of 2 years, 2 months. Analysis with independent samples *t*-test confirms that there was not a statistically significant difference between the age of the ASD and control groups ( $t(50) = 1.50, p = 0.14$ ).

The ASD group had slightly lower cognitive scores than the control group. On the Full Scale of the WASI, standard scores of adolescents in the ASD group ranged from 87 to 121, with a mean of 105.23 and a standard deviation of 8.93. The standard scores of the control group on the Full Scale of the WASI ranged from 90 to 125, with a mean of 110.92 and a standard deviation of 8.33. Independent samples *t*-test indicates that the control group scores on the WASI were significantly higher than the ASD

group's scores ( $t(50) = -2.38, p = 0.02$ ); however, the mean difference between groups was only 5.69, on a standard score scale, and the effect size was small ( $d = -0.32$ ).

Word reading ability was similar between groups. The reading level on the WRAT4 of adolescents in the ASD group ranged from a grade level of 5.2 to 12.9, with a mean of 10.43 and a standard deviation of 2.44. Adolescents in the control group had reading levels on the WRAT4 that ranged from a grade of 5.2 to 12.9, with a mean of 9.80 and a standard deviation of 2.51. Analysis using independent samples  $t$ -test shows that there was not a significant difference in reading level between the ASD and control groups ( $t(50) = 0.92, p = 0.36$ ).

All adolescents with ASD were currently or had previously received psychiatric treatment (see Table 3). Eight participants had previously received only outpatient treatment, while the other 18 adolescents had received inpatient psychiatric treatment at some point in their history in addition to outpatient treatment. Suicidal ideation/actions and aggression towards others were the most common reasons adolescents with ASD received inpatient treatment. For the most recent inpatient psychiatric treatment, 7 adolescents were admitted for suicidal ideation/actions, 6 were admitted for aggression towards others, 1 was suicidal and aggressive, and 4 had other reasons for treatment. Adolescents who had previously received inpatient psychiatric treatment had been out of the hospital for an average of 10.68 months with a standard deviation of 8.65 months. The maximum time between inpatient treatment and assessment was 28.00 months and the minimum was 0.13 months. Three adolescents diagnosed with Autistic Disorder, 10 with Asperger's Disorder, and 5 diagnosed with PDD-NOS had received inpatient

Table 3

*ASD Participant Psychiatric Treatment Data*

		Age of Onset of Psychiatric Problems (in years)	Age of First Outpatient Treatment (in years)	Age of First Inpatient Treatment (in years)	Time Since Last Inpatient Treatment (in months)	Number of Inpatient Treatments <sup>a</sup>	Number of Outpatient Treatments <sup>b</sup>
ASD	<b>Mean</b>	<b>7.38</b>	<b>9.33</b>	<b>11.78</b>	<b>10.68</b>	<b>2.04</b>	<b>3.27</b>
	<i>Standard Deviation</i>	4.48	3.43	2.71	8.65	2.49	1.40
Autistic Disorder	<b>Mean</b>	<b>5.86</b>	<b>7.43</b>	<b>10.33</b>	<b>5.67</b>	<b>0.71</b>	<b>3.00</b>
	<i>Standard Deviation</i>	4.45	3.21	2.52	5.07	0.95	1.00
Asperger's Disorder	<b>Mean</b>	<b>7.33</b>	<b>9.92</b>	<b>12.10</b>	<b>11.21</b>	<b>2.50</b>	<b>2.83</b>
	<i>Standard Deviation</i>	4.87	3.61	2.60	9.24	2.61	1.40
PDD-NOS	<b>Mean</b>	<b>9.00</b>	<b>10.21</b>	<b>12.00</b>	<b>12.61</b>	<b>2.57</b>	<b>4.29</b>
	<i>Standard Deviation</i>	3.83	3.00	3.32	9.43	3.10	1.38

<sup>a</sup> Number of inpatient hospitalizations regardless of length of stay.

<sup>b</sup> Number of different outpatient services and providers that the adolescent has utilized regardless of the length of service.

psychiatric services. All but 3 adolescents with ASD were currently being treated with psychiatric medications. Common medications reported included antidepressants (e.g., Prozac and Zoloft) antipsychotics (e.g., Geodon, Risperdal, and Abilify), mood stabilizers (e.g., Depakote), and medications for attention problems (e.g., Guanfacine, Ritalin, Clonidine, Intuniv, and Vyvanse). The above data show that many adolescents with ASD in this study received multiple treatments and had multiple instances of psychiatric hospitalization due to aggression towards themselves or others.

All adolescents with ASD had at least one comorbid psychiatric diagnosis, as seen in Tables 4 and 5. The most prevalent diagnoses were anxiety disorders, which were present in 58% of adolescents in the ASD group. ADHD was the second most

Table 4

*Number of ASD Participant Comorbid Psychiatric Diagnoses*

		Anxiety <sup>a</sup>	ADHD	Depression	Bipolar Disorder	Mood Disorder- NOS	ODD	Psychosis <sup>b</sup>	Other <sup>c</sup>
ASD	Number	15	14	12	9	5	4	3	2
	Percentage <sup>d</sup>	58%	54%	46%	35%	19%	15%	12%	8%
Autistic Disorder	Number	4	4	3	2	0	1	2	0
Asperger's Disorder	Number	4	6	4	4	2	1	1	1
PDD-NOS	Number	7	4	5	3	3	2	0	1

<sup>a</sup> Includes diagnoses of Generalized Anxiety Disorder, OCD, Separation Anxiety, and Anxiety Disorder-NOS

<sup>b</sup> Includes diagnoses of Psychosis, Schizophrenia, and Schizoaffective Disorder

<sup>c</sup> Includes diagnoses of Tics and Post Traumatic Stress Disorder

<sup>d</sup> The percentage of participants with ASD who received the diagnosis

Table 5

*Number of ASD Participant Comorbid Anxiety Diagnoses*

		Generalized Anxiety Disorder	OCD	Anxiety Disorder NOS	Separation Anxiety
ASD	Number	9	3	2	1
Autistic Disorder	Number	3	0	1	0
Asperger's Disorder	Number	1	2	1	0
PDD-NOS	Number	5	1	0	1

prevalent diagnosis (54% of ASD adolescents). Other common diagnoses included bipolar disorders (35%), Mood Disorder-NOS (19%), and ODD (15%). These high prevalence rates are due to many adolescents having multiple psychiatric diagnoses. Interview with parents revealed that 73% of mothers and 54% of fathers in the ASD group had a psychiatric diagnosis at some point in their life, and 54% had a family member suspected of or diagnosed with ASD. In the control group, 19% of mothers and 27% of fathers had a psychiatric diagnosis, and 23% had a family member suspected of or diagnosed with ASD. According to the National Comorbidity Survey Replication, 46.4% of adults in the United States have had a psychiatric disorder sometime in their life (Kessler, Berglund, Demler, Jin, Merikangas, & Walters, 2005). Therefore, parents in the ASD group had higher prevalence rates than the national sample, while parents in the control group had lower prevalence.

Data from the interview with parents show that the adolescents with ASD had multiple problem behaviors (see Table 6). In the ASD group, 13 adolescents destroyed property, 18 were verbally or physically aggressive, 17 had attempted or threatened suicide, and 15 had previous involvement with law enforcement. This is in contrast to the control group where only 3 destroyed property, 8 were verbally or physically aggressive, 1 threatened or attempted suicide, and 2 were involved with law enforcement. These behaviors show that adolescents with ASD have significant problem behaviors that may be difficult for their parents to manage without help.

Social characteristics data from the parent interview indicate the adolescents in the ASD group had interest in social relationships (see Table 7). In the ASD group, 14

Table 6

*Number of Participant Problem Behaviors*

	Destroys Property	Verbally/ Physically Aggressive	Threatened/ Attempted Suicide	Involved with Law Enforcement
ASD	13	18	17	15
Autistic Disorder	4	5	5	3
Asperger's Disorder	5	8	7	8
PDD-NOS	4	5	5	4
Control	3	8	1	2

adolescents had a best friend, 18 were interested in having more social relationships, 12 had dated or had a romantic relationship, and 19 were interested in dating. On the other hand, 23 of the adolescents in the control group had a best friend, 13 were interested in more social relationships, and 16 were interested in dating. These numbers suggest that adolescents in the control group may be satisfied with their current social relationships, while the adolescents with ASD feel that they need more social connections due to their lack of friends.

## ASEBA Scores

Parent ratings on the ASEBA CBCL show that adolescents in the ASD group had significant psychological and behavior problems. Parents of adolescents in the ASD group had mean ratings on all CBCL scales that were more than one standard deviation above the mean ( $T\text{-score} \geq 60$ ). Parents' mean scores on the Aggressive Behavior, Somatic Complaints, Withdrawn/Depressed, Attention Problems, and Externalizing

Table 7

*Number of Participant Social Characteristics*

	Has Best Friend	Interested in more social relationships	Interested in dating
ASD	14	18	19
Autistic Disorder	4	6	4
Asperger's Disorder	8	7	9
PDD-NOS	2	5	6
Control	23	13	16

scales were in the borderline clinical range ( $T$ -score = 65-69) while their mean ratings on the Anxious/Depressed, Social Problems, Thought Problems, Internalizing, and Total scales were in the clinical range ( $T$ -score  $\geq 70$ ). All mean CBCL scale scores of parents in the control group were within one standard deviation of the mean and in the normal range ( $T$ -score  $\leq 60$ ). These scores indicate that parents of adolescents with ASD perceived their children as having significant psychological and behavioral problems (see Table 8).

The scale scores on the ASEBA YSR show that adolescents with ASD endorse more symptoms of psychological problems than average, as seen in Table 8. The Anxious/Depressed scale was the only YSR scale with a mean score in the borderline clinical range ( $T$ -score = 65-69) for adolescents with ASD. No mean scale scores reached the clinical range ( $T$ -score  $\geq 70$ ). However, the Withdrawn/Depressed, Somatic Complaints, Aggressive Behavior, Social Problems, Thought Problems, Attention Problems, Internalizing, and Total Score scales all had mean scores greater than one



Table 8

*Statistical Data for ASEBA CBCL and YSR for ASD and Control Groups*

		Internalizing						Externalizing			
		Anxious/ Depressed		Withdrawn/ Depressed		Somatic Complaints		Rule-Breaking Behavior		Aggressive Behavior	
		Parent	Child	Parent	Child	Parent	Child	Parent	Child	Parent	Child
ASD	<b>Mean</b>	<b>70.58</b>	<b>65.62</b>	<b>69.12</b>	<b>64.31</b>	<b>65.38</b>	<b>61.00</b>	<b>60.92</b>	<b>56.88</b>	<b>66.62</b>	<b>60.69</b>
	95% CI	66.39- 74.77	61.23- 70.00	64.96- 73.27	60.15- 68.47	61.64- 69.13	57.01- 64.99	58.23- 63.61	54.57- 59.20	62.89- 70.34	56.30- 65.09
	<i>Standard Deviation</i>	<i>10.38</i>	<i>10.86</i>	<i>10.29</i>	<i>10.30</i>	<i>9.27</i>	<i>9.88</i>	<i>6.66</i>	<i>5.73</i>	<i>9.21</i>	<i>10.88</i>
	Percent Clinical <sup>a</sup>	58%	35%	50%	31%	35%	23%	8%	4%	31%	23%
Control	<b>Mean</b>	<b>54.62</b>	<b>53.04</b>	<b>54.00</b>	<b>53.19</b>	<b>52.85</b>	<b>54.31</b>	<b>51.15</b>	<b>51.08</b>	<b>51.58</b>	<b>51.00</b>
	95% CI	51.66- 57.57	51.52- 54.56	52.13- 55.87	51.31- 55.08	51.17- 54.52	51.83- 56.78	50.40- 51.91	50.27- 51.88	50.06- 53.09	50.26- 51.74
	<i>Standard Deviation</i>	<i>7.32</i>	<i>3.76</i>	<i>4.62</i>	<i>4.67</i>	<i>4.14</i>	<i>6.12</i>	<i>1.87</i>	<i>2.00</i>	<i>3.75</i>	<i>1.83</i>
	Percent Clinical	8%	0%	0%	0%	0%	4%	0%	0%	0%	0%

Table 8 (continued)

		Other Problems						Summary Scales					
		Social Problems		Thought Problems		Attention Problems		Internalizing		Externalizing		Total Score	
		Parent	Child	Parent	Child	Parent	Child	Parent	Child	Parent	Child	Parent	Child
ASD	<b>Mean</b>	<b>70.73</b>	<b>64.92</b>	<b>71.23</b>	<b>64.50</b>	<b>68.85</b>	<b>63.35</b>	<b>70.12</b>	<b>64.96</b>	<b>64.42</b>	<b>57.77</b>	<b>70.73</b>	<b>64.19</b>
	95% CI	67.85-73.61	61.13-68.72	68.34-74.13	60.43-68.57	64.90-72.79	59.90-66.79	67.10-73.13	60.68-69.24	61.61-67.24	53.55-61.99	68.42-73.05	60.11-68.28
	<i>Standard Deviation</i>	<i>7.13</i>	<i>9.39</i>	<i>7.17</i>	<i>10.08</i>	<i>9.78</i>	<i>8.52</i>	<i>7.46</i>	<i>10.59</i>	<i>6.98</i>	<i>10.45</i>	<i>5.73</i>	<i>10.12</i>
	Percent Clinical	58%	35%	65%	27%	31%	12%	65%	42%	19%	12%	58%	35%
	<b>Mean</b>	<b>51.35</b>	<b>54.12</b>	<b>51.92</b>	<b>53.54</b>	<b>52.23</b>	<b>52.73</b>	<b>49.35</b>	<b>48.23</b>	<b>44.31</b>	<b>45.42</b>	<b>44.50</b>	<b>47.00</b>
Control	95% CI	50.27-52.42	51.94-56.29	50.19-53.65	51.71-55.37	50.38-54.08	50.97-54.50	45.18-53.52	44.40-52.06	41.02-47.59	43.48-47.37	40.86-48.14	44.03-49.97
	<i>Standard Deviation</i>	<i>2.65</i>	<i>5.38</i>	<i>4.28</i>	<i>4.53</i>	<i>4.58</i>	<i>4.37</i>	<i>10.33</i>	<i>9.49</i>	<i>8.13</i>	<i>4.82</i>	<i>9.02</i>	<i>7.35</i>
	Percent Clinical	0%	4%	4%	0%	4%	0%	4%	0%	0%	0%	0%	0%

Note: CI = Confidence Interval

Means are on a T-score scale.

<sup>a</sup> Represents percentage of participants with a clinical T-score ( $\geq 70$ ).

standard deviation above the mean ( $T\text{-score} \geq 60$ ). On the other hand, all YSR mean scale scores of adolescents in the control group were within one standard deviation of the mean ( $T\text{-score} \leq 60$ ). The elevated scores of adolescents with ASD suggest that even though the scores were not in the clinical range, they reported more psychological and behavioral problems than average adolescents.

### Rating of Functioning Scores

Participant responses on the Rating of Functioning represent parent and adolescent perceptions of the adolescent's current and future (in 6 months) functioning at school, at home, and socially. The frequency of an adolescent's performance of functional behaviors was rated on a likert-type scale (1 = Rarely, 2 = Infrequently, 3 = Sometimes, 4 = Often, 5 = Very Often). Higher numbers indicate better functioning.

Scores for current functioning varied between the three areas assessed, as seen in Table 9. Informants in the ASD group both indicated that the adolescents had the highest current functioning at school, where they performed functional behaviors "sometimes" (Parent Score = 3.13; Adolescent Score = 3.65). Adolescents in the ASD group had the lowest scores for current social functioning since they performed functional behaviors "infrequently," as reported by both raters (Parent Score = 2.42; Adolescent Score = 2.82). Scores for current functioning of adolescents in the control group also placed their highest current functioning at school, where they performed functional behaviors "often" (Parent Score = 4.53; Adolescent Score = 4.38), and their lowest scores in social functioning, where they performed functional behaviors

Table 9

*Means and Standard Deviations for Rating of Functioning (Current)*

		School		Home		Social		Total	
		Parent	Child	Parent	Child	Parent	Child	Parent	Child
ASD	<b>Mean</b>	<b>3.13</b>	<b>3.65</b>	<b>2.71</b>	<b>3.38</b>	<b>2.42</b>	<b>2.82</b>	<b>2.79</b>	<b>3.28</b>
	<i>Standard Deviation</i>	<i>0.82</i>	<i>0.60</i>	<i>0.69</i>	<i>0.90</i>	<i>0.58</i>	<i>0.66</i>	<i>0.53</i>	<i>0.54</i>
Control	<b>Mean</b>	<b>4.53</b>	<b>4.38</b>	<b>4.27</b>	<b>4.20</b>	<b>3.74</b>	<b>3.63</b>	<b>4.23</b>	<b>4.06</b>
	<i>Standard Deviation</i>	<i>0.43</i>	<i>0.41</i>	<i>0.47</i>	<i>0.45</i>	<i>0.47</i>	<i>0.56</i>	<i>0.31</i>	<i>0.36</i>

*Note: Scores represent mean ratings for the frequency of the performance of functional behaviors, higher is better. 1 = Rarely, 2 = Infrequently, 3 = Sometimes, 4 = Often, 5 = Very Often*

“sometimes” (Parent Score = 3.74; Adolescent Score = 3.63). A pattern of interest is that, for current functioning, the self-report scores of adolescents in the ASD group were higher than the parent-report scores in all areas. However, the current self-report scores of adolescents in the control group were lower than the parent-report scores in all areas. Additionally, parents and adolescents in both groups rated functioning at school the highest, followed by home, and then social.

Similar patterns emerged in the scores of future functioning (in 6 months), as seen in Table 10. Adolescents in the ASD group had the highest future functioning scores for school functioning, where they were predicted to perform functional behaviors “sometimes” and “often” (Parent Score = 3.52; Adolescent Score = 4.11), and the lowest scores in social functioning, where they were predicted to perform functional behaviors “infrequently” and “sometimes” (Parent Score = 2.80; Adolescent Score = 3.92). Adolescents in the control group also had the highest scores for future school functioning, where they were predicted to perform functional behaviors “often” (Parent

Table 10

*Means and Standard Deviations for Rating of Functioning Future (In 6 Months)*

		School		Home		Social		Total	
		Parent	Child	Parent	Child	Parent	Child	Parent	Child
ASD	<b>Mean</b>	<b>3.52</b>	<b>4.11</b>	<b>3.13</b>	<b>3.92</b>	<b>2.80</b>	<b>3.92</b>	<b>3.16</b>	<b>3.76</b>
	<i>Standard Deviation</i>	0.72	0.63	0.64	0.95	0.64	0.85	0.54	0.64
Control	<b>Mean</b>	<b>4.62</b>	<b>4.54</b>	<b>4.41</b>	<b>4.43</b>	<b>3.85</b>	<b>3.82</b>	<b>4.33</b>	<b>4.24</b>
	<i>Standard Deviation</i>	0.38	0.45	0.43	0.46	0.50	0.62	0.30	0.40

*Note: Scores represent mean ratings for the frequency of the performance of functional behaviors, higher is better. 1 = Rarely, 2 = Infrequently, 3 = Sometimes, 4 = Often, 5 = Very Often*

Score = 4.62; Adolescent Score = 4.54) and the lowest scores for social functioning, where they were predicted to perform functional behaviors sometimes (Parent Score = 3.85; Adolescent Score = 3.82). Additionally, for the adolescents in the ASD group, self-report scores were higher than parent-report scores for school, home, and social functioning. Adolescents in the control group had self-report scores that were lower than parent-report for school and social functioning, but higher scores for home functioning. An interesting finding is that adolescents and parents in both groups indicated that the adolescents would have better functioning, in all areas, just 6 months in the future. This perception of higher future functioning for adolescents with and without ASD may represent optimism about the future.

### Research Hypothesis 1

*Scale scores from the ASEBA YSR self-report of participants with ASD will be significantly lower than scale scores on the ASEBA CBCL parent-report on the*

*following composite scale and subscales: Total, Rule-Breaking Behavior, Attention Problems, and Aggressive Behavior.*

#### Total Score

The Total scale on the ASEBA was examined with a paired samples *t*-test (see Table 11). The self-report scores for adolescents with ASD were significantly lower than parent-report scores ( $t(25) = 3.34, p = 0.003$ ). The effect size of this difference indicated a medium effect ( $d = 0.66$ ). This result differed from the control group where adolescents had higher ratings on the Total scale than their parents, but the difference was not statistically significant ( $t(25) = -1.36, p = 0.187$ ). Hypothesis 1 is supported by these results since adolescents with an ASD endorsed significantly fewer problems than their parents reported on the ASEBA Total score. This indicates that adolescents with ASD may not be aware of their overall level of psychological and behavior problems, while adolescents in the control group were aware of their level of problem behaviors.

#### Rule-Breaking Behavior

Paired samples *t*-test shows that, for adolescents in the ASD group, self-report scores were significantly lower on the Rule-Breaking Behavior scale than parent-report scores, as described in Table 12 ( $t(25) = 3.62, p = 0.001$ ). This difference indicated a medium effect of rater on Rule-Breaking Behavior ( $d = 0.69$ ). On the other hand, there was little difference between self- and parent-report scores in the control group ( $t(25) = 0.14, p = 0.89$ ). These analyses support Hypothesis 1 since adolescents with an ASD

Table 11

*Statistical Values for ASEBA Total t-tests*

	<i>t</i>	<i>d</i>
ASD: Parent vs Adolescent	3.34*	0.66
Control: Parent vs Adolescent	-1.36	-0.27

*Note:* \* Significant at the  $p \leq 0.05$  level

Table 12

*Statistical Values for ASEBA Rule Breaking Behavior t-tests*

	<i>t</i>	<i>d</i>
ASD: Parent vs Adolescent	3.62*	0.69
Control: Parent vs Adolescent	0.14	0.27

*Note:* \* Significant at the  $p \leq 0.05$  level

endorsed fewer problems than their parents reported on the Rule-Breaking Behavior scale. The difference between parent and adolescent report shows that adolescents with ASD were not aware of all of their rule-breaking behaviors, while adolescents in the control group demonstrated awareness of this behavior.

### Attention Problems

Adolescents in the ASD group endorsed significantly fewer symptoms on the Attention Problems scale than their parents reported ( $t(25) = 2.27, p = 0.03$ ). The effect size in this case was medium ( $d = 0.43$ ). There was no significant difference between self- and parent-report of attention problems in the control group, as seen in Table 13 ( $t(25) = -0.42, p = 0.68$ ). These analyses support Hypothesis 1 since self-reported attention problems of adolescents with ASD were significantly lower than parent-reported problems. Adolescents with ASD were not aware of all their attention problems, while adolescents in the control group were aware of any problems.

Table 13

*Statistical Values for ASEBA Attention Problems t-tests*

	<i>t</i>	<i>d</i>
ASD: Parent vs Adolescent	2.27*	0.43
Control: Parent vs Adolescent	-0.42	-0.08

*Note:* \* Significant at the  $p \leq 0.05$  level



### Aggressive Behavior

Results of a paired samples  $t$ -test, seen in Table 14, demonstrate that adolescents in the ASD group endorsed fewer aggressive behavior symptoms than their parents reported ( $t(25) = 3.47, p = 0.002$ ). This difference between self- and parent-report represented a medium effect size for informant ( $d = 0.66$ ). Conversely, there was no significant difference between self- and parent-report in the control group ( $t(25) = 0.71, p = 0.48$ ). As with the other analyses, the Hypothesis 1 is supported. Adolescents with ASD were not fully aware of their aggressive behavior, while adolescents in the control group demonstrated awareness of any aggressive behavior problems they exhibited.

### Research Hypothesis 2

*The composite Externalizing score on the ASEBA YSR self-report of participants with ASD will be significantly higher than the composite Internalizing score on the ASEBA YSR self-report.*

Table 14

*Statistical Values for ASEBA Aggressive Behavior  $t$ -tests*

	$t$	$d$
ASD: Parent vs Adolescent	3.47*	0.66
Control: Parent vs Adolescent	0.71	0.14

*Note:* \* Significant at the  $p \leq 0.05$  level

The difference between self-reported externalizing and internalizing symptoms on the ASEBA YSR was analyzed using paired samples  $t$ -test. For the ASD group, the Externalizing scale was significantly lower than the Internalizing scale (see Tables 15 and 16,  $t(25) = -3.69, p = 0.001$ ). The effect size for the difference between externalizing and internalizing scales was medium to large ( $d = -0.70$ ). For the control group, the ratings on the Externalizing scale were also lower than the Internalizing scale ratings; however, the difference was not statistically significant ( $t(25) = -1.91, p = 0.07$ ).

A repeated measures ANOVA was also used to analyze the difference between internalizing and externalizing self-report scales. Results show that overall Externalizing scale scores were significantly lower than Internalizing scale scores ( $F(1,50) = 16.76, p < 0.001$ ), and adolescents in the ASD group had significantly higher

Table 15

*Statistical Values for ASEBA YSR Internalizing vs. Externalizing Scale*

	$F$	$t$	Partial $\eta^2$ (Partial Eta-Squared)	$d$
Externalizing vs. Internalizing	16.76*	--	0.25	--
ASD vs. Control	42.74*	--	0.46	--
Interaction	3.22	--	0.06	--
ASD: Externalizing vs. Internalizing	--	-3.69*	--	-0.70
Control: Externalizing vs. Internalizing	--	-1.91	--	-0.36

Note: \* Significant at the  $p \leq 0.05$  level

Table 16

*YSR Self-Report Internalizing and Externalizing Means*

	Internalizing	Externalizing
ASD	64.96	57.77
Control	48.23	45.42

scores on both scales than the control group ( $F(1,50) = 42.74, p < 0.001$ ). The interaction between ASD status and Externalizing versus Internalizing scales was not significant ( $F(1,50) = 3.22, p = 0.08$ ). The lack of significance in the interaction shows that both the ASD group and the control group had scores on the Externalizing scale that were lower than the Internalizing scale.

These analyses do not support Hypothesis 2 since the difference between Internalizing and Externalizing self-report ratings was in the opposite direction from what was hypothesized. It was predicted that the self-report would be higher due to most adolescents being admitted to psychiatric inpatient treatment for aggression. However, the higher Internalizing scale suggests that adolescents with ASD perceive internalizing symptoms (anxiety, depression, and somatic complaints) as a greater problem than externalizing behaviors (rule-breaking and aggression).

### Research Hypothesis 3

*The average score for current functioning on the Rating of Functioning self-report of participants with ASD will be significantly higher than the average score for*

*current functioning on the Rating of Functioning parent-report.*

Parent- and self-report ratings of current functioning on the Rating of Functioning were analyzed using paired samples *t*-tests (see Table 17). The results indicate that self-reported current functioning of adolescents with ASD was significantly higher than parent-reported current functioning ( $t(25) = 3.60, p = 0.001$ ). On the other hand, self-reported current functioning of adolescents in the control group was significantly lower than their parent-reported current functioning ( $t(25) = -2.67, p = 0.01$ ). Both significant differences had a medium effect size (ASD  $d = 0.68$ ; Control  $d = -0.51$ ). These results support Hypothesis 3 since adolescents with ASD reported higher current functioning than the parent report. This difference suggests that adolescents with ASD may over-estimate their functioning and be unaware of functional problems, while adolescents in the control group may under-report their own functioning.

Table 17

*Statistical Values for Rating of Functioning Current:*

*Self vs. Parent Report*

	<i>t</i>	<i>d</i>
ASD: Adolescent vs. Parent	3.60*	0.68
Control: Adolescent vs. Parent	-2.67*	- 0.51

*Note:* \* Significant at the  $p \leq 0.05$  level

### Research Hypothesis 4

*The average score for future functioning (in 6 months) on the Rating of Functioning self-report of participants with ASD will be significantly higher than the average score for future functioning (in 6 months) on the Rating of Functioning parent-report.*

Results of the paired samples *t*-test show that the self-reported future functioning of adolescents with ASD was significantly higher than parent-reported future functioning (see Table 18,  $t(25) = 4.19$ ,  $p < 0.001$ ), and the effect size of this difference was large ( $d = 0.80$ ). However, even though the self-reported future functioning of adolescents in the control group was lower than parent-reported future functioning, the difference was not statistically significant ( $t(25) = -1.26$ ,  $p = 0.22$ ). These results support Hypothesis 4 since adolescents with ASD reported significantly higher future functioning than their parents reported. The difference between parent- and self-report suggests that even though both parents and adolescents indicated that they

Table 18

*Statistical Values for Rating of Functioning Future  
(in 6 months): Self vs. Parent Report*

	<i>t</i>	<i>d</i>
ASD: Adolescent vs. Parent	4.19*	0.80
Control: Adolescent vs. Parent	-1.26	-0.24

*Note:* \* Significant at the  $p \leq 0.05$  level

believed adolescents with ASD would function better in 6 months, adolescents with ASD still demonstrated a lack of awareness of functional problems they may have in the future.

### Research Hypothesis 5

*The average score for future functioning (in 6 months) on the Rating of Functioning self-report of participants with ASD will be significantly higher than the average score for current functioning on the Rating of Functioning self-report.*

Self-reported future functioning for adolescents with ASD was significantly higher than self-reported current functioning, as seen in Table 19 ( $t(25) = 7.59, p < 0.001$ ). Adolescents in the control group also reported significantly higher future functioning than current functioning ( $t(25) = 4.84, p < 0.001$ ). Both significant differences had a large effect size (ADS  $d = 1.44$ ; Control  $d = 0.92$ ). These analyses support Hypothesis 5 since adolescents with ASD reported that their future functioning

Table 19

*Statistical Values for Self-Report Rating of Functioning  
Future (in 6 months) vs. Current*

	<i>t</i>	<i>d</i>
ASD: Future vs. Current	7.59*	1.44
Control: Future vs. Current	4.84*	0.92

*Note:* \* Significant at the  $p \leq 0.05$  level

would be higher than their current functioning. Reporting of better functioning by adolescents with and without ASD suggests that both groups are optimistic about improvement of their functional abilities in the future.

#### Research Hypothesis 6

*The parent-report ASEBA CBCL Total score for participants with ASD will be significantly positively correlated with difference scores between participants' self-report on the Rating of Functioning scale and the parent-report on the same scale.*

To examine this hypothesis, the total score of the parent-report on the Rating of Functioning was subtracted from the total score of the self-report on the Rating of Functioning. This generated a difference score. A positive value indicated that the self-report was higher than the parent-report, while a negative value indicated that the self-report was lower. Next, the difference score was correlated with the parent-report Total score on the CBCL. A Pearson bivariate correlation was used to examine the relationship between these two variables. Results of the correlation indicated that for adolescents with ASD, the difference between self- and parent-reported functioning was not significantly correlated with the parent CBCL Total score ( $r = 0.317, p = 0.11$ ). However, this correlation was significant for the control group ( $r = 0.62, p = 0.001$ ). The results of this analysis indicate that Hypothesis 6 cannot be supported since the correlation was not significant for adolescents with ASD. Lack of a significant correlation indicates that parent-reported severity of psychological and behavior problems was not related to awareness of functioning problems (difference between

self- and parent-report on Rating of Functioning) for adolescents with ASD. A summary of the results of the research hypotheses can be seen in Table 20.

### Research Question 1

*What is the difference between parent- and self-report scales on the ASEBA CBCL and YSR for participants with ASD and participants in the control group and what are any differences between groups?*

#### Anxious/Depressed

Repeated-measures ANOVA revealed that there was a significant difference between parent- and self-report on the Anxious/Depressed scale, as seen in Tables 21 and 22. In general, adolescents endorsed significantly fewer problems than parents reported ( $F(1,50) = 7.83, p = 0.01$ ). Scores on the Anxious/Depressed scale for the ASD group were significantly higher than scores on this scale for the control group ( $F(1,50) = 47.64, p < 0.001$ ). The interaction between informant and group was not statistically significant, ( $F(1,50) = 2.10, p = 0.15$ ). A paired samples  $t$ -test indicated that self-report of adolescents in the ASD group was significantly lower on the Anxious/Depressed scale than parent-report ( $t(25) = 2.53, p = 0.02$ ); however, there was no significant difference between self- and parent-report for the control group ( $t(25) = 1.24, p = 0.23$ ). These analyses show that adolescents with ASD were not aware of all of their anxiety and depression problems. However, both parents and adolescents in the ASD group



Table 20

*Results of Hypotheses*

Hypothesis Summary	Results	Hypothesis Status
<u>Hypothesis 1:</u> The self-report on the ASEBA of adolescents with ASD will be significantly lower than the parent-report on the ASEBA for the Total, Rule-Breaking Behavior, Attention Problems, and Aggressive Behavior scales.	Self-report scores of adolescents with ASD were significantly lower than parent-report on Total Score, Rule-Breaking Behavior, Attention Problems, and Aggressive Behavior scales.	Supported
<u>Hypothesis 2:</u> The self-report Externalizing score will be significantly higher than the self-report Internalizing score on the ASEBA for adolescents with ASD.	The Internalizing score was significantly higher than the Externalizing score for adolescents with ASD.	Not Supported
<u>Hypothesis 3:</u> The average self-report score will be higher than the average parent-report score for current functioning on the Rating of Functioning for adolescents with ASD.	Average self-report scores for current functioning on the Rating of Functioning were significantly higher than average parent-report scores for adolescents with ASD.	Supported
<u>Hypothesis 4:</u> The average self-report score will be higher than the average parent-report score for future functioning on the Rating of Functioning for adolescents with ASD.	Average self-report scores for future functioning on the Rating of Functioning were significantly higher than average parent-report scores for adolescents with ASD.	Supported
<u>Hypothesis 5:</u> The average self-report for future functioning will be significantly higher than the average self-report for current functioning on the Rating of Functioning for adolescents with ASD.	Self-report of future functioning was significantly higher than self-report of current functioning for adolescents with ASD.	Supported
<u>Hypothesis 6:</u> The ASEBA Total score on the parent-report will be significantly correlated with the difference between self- and parent-report of current functioning on the Rating of Functioning for adolescents with ASD.	The parent-report Total score was not significantly correlated with the difference between self- and parent-report of current functioning for adolescents with ASD.	Not Supported

Table 21

*Statistical Values for ASEBA CBCL and YSR Anxious/Depressed*

	<i>F</i>	<i>t</i>	Partial $\eta^2$ (Partial Eta-Squared)	<i>d</i>
Parent vs Adolescent	7.83*	--	0.14	--
ASD vs Control	47.64*	--	0.49	--
Interaction	2.10	--	0.04	--
ASD: Parent vs Adolescent	--	2.53*	--	0.48
Control: Parent vs Adolescent	--	1.24	--	0.24

*Note:* \* Significant at the  $p \leq 0.05$  level

Table 22

*ASEBA Anxious/Depressed Means*

	Parent	Adolescent
ASD	70.58	65.62
Control	54.62	53.04

reported that adolescents with ASD had more symptoms of anxiety and depression than adolescent in the control group, which suggests awareness of some symptoms.

### Withdrawn/Depressed

The analysis of the Withdrawn/Depressed scale can be seen in Tables 23 and 24. It indicates that self-report scores were significantly lower than parent-report scores ( $F(1,50) = 5.40, p = 0.02$ ). Additionally, scores on the Withdrawn/Depressed scale for the ASD group were significantly higher than scores on this scale for the control group ( $F(1,50) = 49.97, p < 0.001$ ). The interaction between informant and group was not significant ( $F(1,50) = 2.74, p = 0.10$ ). A paired samples  $t$ -test revealed that self-report on the Withdrawn/Depressed scale in the ASD group was significantly lower than

Table 23

*Statistical Values for ASEBA CBCL and YSR Withdrawn/Depressed*

	$F$	$t$	Partial $\eta^2$ (Partial Eta-Squared)	$d$
Parent vs Adolescent	5.40*	--	0.10	--
ASD vs Control	49.97*	--	0.50	--
Interaction	2.74	--	0.05	--
ASD: Parent vs Adolescent	--	2.21*	--	0.42
Control: Parent vs Adolescent	--	0.76	--	0.14

*Note:* \* Significant at the  $p \leq 0.05$  level

Table 24

*ASEBA Withdrawn/Depressed Means*

	Parent	Adolescent
ASD	69.12	64.31
Control	54.00	53.19

parent-report ( $t(25) = 2.21, p = 0.04$ ). On the other hand, there was not a significant difference between self- and parent-report in the control group ( $t(25) = 0.76, p = 0.45$ ). The analyses indicate that adolescents with ASD were not aware of all of their symptoms of withdrawal/depression; however, they demonstrated some awareness since they endorsed more symptoms than adolescents in the control group.

### Somatic Complaints

The repeated measured ANOVA shows that overall, there was not a significant difference between adolescent and parent scores on the Somatic Complaints scale, as seen in Tables 25 and 26 ( $F(1,50) = 1.23, p = 0.27$ ). Somatic Complaints scores of informants in the ASD group were higher than the scores on this scale of informants in the control group ( $F(1,50) = 32.58, p < 0.001$ ). The interaction between ASD status and informant was significant ( $F(1,50) = 4.91, p = 0.03$ ). The significant interaction represents the fact that adolescents with ASD endorsed fewer somatic symptoms than their parents reported, while adolescents in the control group endorsed more somatic symptoms than their parents reported. A paired samples *t*-test indicated that self-report

Table 25

*Statistical Values for ASEBA CBCL and YSR Somatic Complaints*

	<i>F</i>	<i>t</i>	Partial $\eta^2$ (Partial Eta-Squared)	<i>d</i>
Parent vs Adolescent	1.23	--	0.02	--
ASD vs Control	32.58*	--	0.40	--
Interaction	4.91*	--	0.09	--
ASD: Parent vs Adolescent	--	1.77	--	0.34
Control: Parent vs Adolescent	--	-1.58	--	-0.30

*Note:* \* Significant at the  $p \leq 0.05$  level

Table 26

*ASEBA Somatic Complaints Means*

	Parent	Adolescent
ASD	65.38	61.00
Control	52.85	54.31

of adolescents in the ASD group was lower than parent-report for Somatic Complaints, but the difference was not statistically significant ( $t(25) = 1.77, p = 0.09$ ). Self-report of adolescents in the control group was higher than parent-report, but the difference also was not statistically significant ( $t(25) = -1.58, p = 0.13$ ). These results show that adolescents with ASD had more somatic symptoms than adolescents in the control group, and adolescents with ASD demonstrated awareness of these symptoms.

### Social Problems

Results of the repeated measures ANOVA show that there was not a statistically significant difference between overall parent and adolescent scores on the Social Problems scale, as seen in Tables 27 and 28 ( $F(1,50) = 1.71, p = 0.20$ ). However, scores for the ASD group were significantly higher than scores for the control group ( $F(1,50) = 112.90, p < 0.001$ ). The interaction between group and informant was significant ( $F(1,50) = 13.64, p = 0.001$ ). The significant interaction shows that adolescents with ASD reported fewer social problems than the parent-report, while adolescents in the control group reported more social problems than the parent-report. Paired samples  $t$ -test shows that adolescents in the ASD group endorsed significantly fewer symptoms of social problems than their parents reported ( $t(25) = 2.70, p = 0.01$ ), while adolescents in the control group endorsed significantly more symptoms of social problems than their parents reported ( $t(25) = -3.14, p = 0.004$ ). These analyses indicate that the adolescents with ASD lacked full awareness of their social problems, while adolescents in the control group believed that they had more social problems than their parents perceived.

Table 27

*Statistical Values for ASEBA CBCL and YSR Social Problems*

	<i>F</i>	<i>t</i>	Partial $\eta^2$ (Partial Eta-Squared)	<i>d</i>
Parent vs Adolescent	1.71	--	0.03	--
ASD vs Control	112.90*	--	0.69	--
Interaction	13.64*	--	0.21	--
ASD: Parent vs Adolescent	--	2.70*	--	0.51
Control: Parent vs Adolescent	--	-3.14*	--	-0.60

*Note:* \* Significant at the  $p \leq 0.05$  level

Table 28

*ASEBA Social Problems Means*

	Parent	Adolescent
ASD	70.73	64.92
Control	51.35	54.12

However, adolescents with ASD demonstrated some self-awareness of social problems since they endorsed more symptoms than adolescents in the control group.

### Thought Problems

Repeated measures ANOVA indicated that there were significant differences between self- and parent-report on the Thought Problems scale, as seen in Tables 29 and 30 ( $F(1,50) = 4.56, p = 0.04$ ). Additionally, scores on this scale for the ASD group were significantly higher than scores for the control group ( $F(1,50) = 101.64, p < 0.001$ ). The interaction between ASD status and informant was statistically significant ( $F(1,50) = 12.14, p = 0.001$ ). The significant interaction indicates that adolescents with ASD endorsed fewer symptoms of Thought Problems than their parents reported, while adolescents in the control group endorsed more symptoms of Thought Problems than their parents reported. A paired samples *t*-test demonstrated that the self-reported Thought Problems scores of adolescents in the ASD group were significantly lower than the parent-report scores on the same scale, ( $t(25) = 3.16, p = 0.004$ ). However, even though self-report of adolescents in the control group was higher than parent-report, the difference was not statistically significant ( $t(25) = -1.47, p = 0.15$ ). These differences show that adolescents in the control group were aware of any thought problems that they had. However, adolescents in the ASD group demonstrated a lack of awareness of some symptoms of thought problems, although they were aware of some issues since they endorsed more symptoms of thought problems.



Table 29

*Statistical Values for ASEBA CBCL and YSR Thought Problems*

	<i>F</i>	<i>t</i>	Partial $\eta^2$ (Partial Eta-Squared)	<i>d</i>
Parent vs Adolescent	4.56*	--	0.08	--
ASD vs Control	101.64*	--	0.67	--
Interaction	12.14*	--	0.20	--
ASD: Parent vs Adolescent	--	3.16*	--	0.60
Control: Parent vs Adolescent	--	-1.47	--	-0.28

*Note:* \* Significant at the  $p \leq 0.05$  level

Table 30

*ASEBA Thought Problems Means*

	Parent	Adolescent
ASD	71.23	64.50
Control	51.92	53.54

### Attention Problems

The results of a repeated-measures ANOVA indicated that there was not an overall significant difference between adolescent and parent scores on the Attention Problems scale, as seen in Tables 31 and 32 ( $F(1,50) = 3.44, p = 0.70$ ). However, the ASD group as a whole had significantly higher scores than the control group's scores on this scale ( $F(1,50) = 84.72, p < 0.001$ ), and the interaction of group by informant was significant ( $F(1,50) = 4.95, p = 0.03$ ). The significant interaction shows that adolescents in the ASD group endorsed fewer symptoms of attention problems than their parents reported while there was no difference between parent- and self-report in the control group. Results of a paired samples *t*-test are reported in the Hypothesis 1 section. This analysis shows that adolescents with ASD had significantly more attention problems than adolescents in the control group.

Table 31

*Statistical Values for ASEBA CBCL and YSR Attention Problems*

	<i>f</i>	Partial $\eta^2$ (Partial Eta-Squared)
Parent vs Adolescent	3.44	0.06
ASD vs Control	84.72*	0.63
Interaction	4.95*	0.09

*Note:* \* Significant at the  $p \leq 0.05$  level

Table 32

*ASEBA Attention Problems Means*

	Parent	Adolescent
ASD	68.85	63.35
Control	52.23	52.73

## Rule-Breaking Behavior

Results of the repeated-measures ANOVA show that parent-report of Rule-Breaking Behavior was significantly higher than adolescent self-report on this scale, as seen in Tables 33 and 34 ( $F(1,50) = 10.98, p = 0.002$ ). Additionally, there was a significant difference between the ASD and control group since the ASD group's Rule-Breaking Behavior scores were significantly higher than the control group's scores ( $F(1,50) = 48.79, p < 0.001$ ). The interaction between informant and group was significant ( $F(1,50) = 10.17, p = 0.002$ ). The significant interaction shows that adolescents with ASD endorsed fewer symptoms of Rule-Breaking Behavior than their parents reported, while there was not a difference between parent- and self-report of Rule-Breaking Behavior in the control group. Results of a paired samples *t*-test are presented in the Hypothesis 1 section. These results demonstrate that the adolescents with ASD had significantly more symptoms of rule-breaking behavior than adolescents in the control group.

Table 33

*Statistical Values for ASEBA CBCL and YSR Rule-Breaking Behavior*

	<i>F</i>	Partial $\eta^2$ (Partial Eta-Squared)
Parent vs Adolescent	10.98*	0.18
ASD vs Control	48.79*	0.49
Interaction	10.17*	0.17

*Note:* \* Significant at the  $p \leq 0.05$  level

Table 34

*ASEBA Rule Breaking-Behavior Means*

	Parent	Adolescent
ASD	60.92	56.88
Control	51.15	51.08

### Aggressive Behavior

The repeated-measures ANOVA indicated that parent-report on the Aggressive Behavior scale was significantly higher than adolescent self-report on this scale, as can be seen in Tables 35 and 36 ( $F(1,50) = 11.85, p = 0.001$ ). Additionally, the ASD group as a whole had higher scores on the Aggressive Behavior scale than the control group scores on this scale ( $F(1,50) = 45.62, p < 0.001$ ). The interaction between ASD status and informant also was statistically significant ( $F(1,50) = 8.01, p = 0.01$ ). The significant interaction indicates that adolescents in the ASD group endorsed fewer symptoms of aggressive behavior than their parents reported, while there was not a difference between self- and parent-report in the control group. Results of a paired-sample  $t$ -test are presented in the Hypothesis 1 section. These analyses show that adolescents with ASD had significantly more aggressive behaviors than adolescents in the control group, and they demonstrated some awareness of their aggressive behavior

Table 35

*Statistical Values for ASEBA CBCL and YSR Aggressive Behavior*

	$F$	Partial $\eta^2$ (Partial Eta-Squared)
Parent vs Adolescent	11.85*	0.19
ASD vs Control	45.62*	0.48
Interaction	8.01*	0.14

*Note:* \* Significant at the  $p \leq 0.05$  level

Table 36

*ASEBA Aggressive Behavior Means*

	Parent	Adolescent
ASD	66.62	60.69
Control	51.58	51.00

since they endorsed more symptoms of aggression than adolescents in the control group.

## Internalizing

Results of the repeated measures ANOVA indicated that parent-report scores on the Internalizing scale were significantly higher than adolescent self-report scores, as seen in Tables 37 and 38 ( $F(1,50) = 4.43, p = 0.04$ ). Additionally, the ASD group had significantly higher scores on the Internalizing scale than the control group's scores on the same scale ( $F(1,50) = 73.36, p < 0.001$ ). The interaction was not statistically significant ( $F(1,50) = 1.84, p = 0.18$ ). A paired sample  $t$ -test indicated that the parent-report Internalizing scores were significantly higher than the self-report scores for the adolescents with ASD, ( $t(25) = 2.34, p = 0.03$ ). There was not a significant difference between parent- and self-report in the control group ( $t(25) = 0.56, p = 0.58$ ). These scores show that adolescents with ASD were not aware of many of their internalizing symptoms; however, they demonstrated some awareness since they reported more internalizing symptoms than the control group.

Table 37

*Statistical Values for ASEBA CBCL and YSR Internalizing Scale*

	<i>F</i>	<i>t</i>	Partial $\eta^2$ (Partial Eta-Squared)	<i>d</i>
Parent vs Adolescent	4.43*	--	0.08	--
ASD vs Control	73.36*	--	0.60	--
Interaction	1.84	--	0.04	--
ASD: Parent vs Adolescent	--	2.34*	--	0.44
Control: Parent vs Adolescent	--	0.56	--	0.11

*Note:* \* Significant at the  $p \leq 0.05$  level

Table 38

*ASEBA Internalizing Scale Means*

	Parent	Adolescent
ASD	70.12	64.96
Control	49.35	48.23

### Externalizing

Analysis with repeated measures ANOVA indicated parent-report scores on the Externalizing scale were significantly higher than adolescent self-report, as seen in Tables 39 and 40 ( $F(1,50) = 5.58, p = 0.02$ ). The ASD group had significantly higher scores on the Externalizing scale than the control group's scores on this scale ( $F(1,50) = 77.95, p < 0.001$ ). The interaction was also significant ( $F(1,50) = 10.98, p = 0.002$ ). The significant interaction indicates that adolescents with ASD reported fewer Externalizing symptoms than on the parent-report, while there was not a difference in Externalizing scores in the control group. Paired sample  $t$ -test demonstrated that parent-report Externalizing scores were significantly higher than the self-report scores of adolescents with ASD ( $t(25) = 3.78, p = 0.001$ ). On the other hand, the self-report of adolescents in

Table 39

*Statistical Values for ASEBA CBCL and YSR Externalizing Scale*

	$F$	$t$	Partial $\eta^2$ (Partial Eta-Squared)	$d$
Parent vs Adolescent	5.58*	--	0.10	--
ASD vs Control	77.95*	--	0.61	--
Interaction	10.98*	--	0.18	--
ASD: Parent vs Adolescent	--	3.78*	--	0.72
Control: Parent vs Adolescent	--	-0.72	--	-0.14

*Note:* \* Significant at the  $p \leq 0.05$  level



Table 40

*ASEBA Externalizing Scale Means*

	Parent	Adolescent
ASD	64.42	57.77
Control	44.31	45.42

the control group was higher than parent report, although the difference was not statistically significant ( $t(25) = -0.72, p = 0.48$ ). These analyses show that adolescents with ASD are not fully aware of their Externalizing symptoms; however, they demonstrated some awareness since they endorsed more externalizing symptoms than adolescents in the control group.

## Total Score

Analysis with repeated measures ANOVA indicated that there was not a statistically significant difference between parent and adolescent scores on the Total, as seen in Tables 41 and 42 ( $F(1,50) = 2.26, p = 0.14$ ). However, the ASD group had significantly higher scores on the Total scale than the control group's scores on this scale ( $F(1,50) = 138.70, p < 0.001$ ), and the interaction between rater and group was significant ( $F(1,50) = 11.31, p = 0.001$ ). The significant interaction indicates that adolescents with ASD endorsed fewer psychological and behavior problems than their parents reported, while adolescents in the control group endorsed more symptoms than their parents reported. Additionally, results of a paired samples  $t$ -test are presented in

Table 41

*Statistical Values for ASEBA CBCL and YSR Total Score*

	<i>F</i>	Partial $\eta^2$ (Partial Eta-Squared)
Parent vs Adolescent	2.26	0.04
ASD vs Control	138.70*	0.74
Interaction	1.31*	0.18

*Note:* \* Significant at the  $p \leq 0.05$  level

Table 42

*ASEBA Total Score Means*

	Parent	Adolescent
ASD	70.73	64.19
Control	44.50	47.00

the Hypothesis 1 section. These results indicate that adolescents with ASD endorsed more psychological and behavioral symptoms on the ASEBA than adolescents in the control group, and parent-report of psychological and behavior problems was higher for the ASD group than for the control group. Adolescents with ASD also demonstrated some level of self-awareness of their psychological problems since they endorsed more symptoms than adolescents in the control group.

### Research Question 2

*What is the difference in the average score between self- and parent-reports on the Rating of Functioning for participants with ASD and participants in the control group and what are any differences between groups?*

#### Rating of Functioning: Rater vs. Time Period vs. Group

Results of a three-way ANOVA show that there were significant main effects and interactions (see Tables 43 and 44). Overall, adolescent-reported functioning was higher than parent-reported functioning ( $F(1,50) = 7.90, p = 0.01$ ). Additionally, rating of future functioning was significantly higher than rating of current functioning ( $F(1,50) = 83.05, p < 0.001$ ). The ASD group had significantly lower functioning scores (current and future combined) than the control group ( $F(1,50) = 95.95, p < 0.001$ ). The interaction between rater and time was significant, which indicates that the difference between self-report current and future functioning is greater than the difference between parent-reported current and future functioning ( $F(1,50) = 4.13, p = 0.05$ ). Also, the

Table 43

*Three-Way ANOVA on Rating of Functioning Results: Rater vs. Time Period vs. Group*

	<i>F</i>	Partial $\eta^2$ (Partial Eta-Squared)
Rater (Adolescent vs. Parent)	7.90*	0.14
Time (Current vs. Future)	83.05*	0.62
Group (ASD vs. Control)	95.05*	0.66
Rater vs. Time	4.13*	0.08
Rater vs. Group	20.65*	0.29
Time vs. Group	20.25*	0.29
Rater vs. Time vs. Group	0.11	0.00

*Note:* \* Significant at the  $p \leq 0.05$  level

Table 44

*Rating of Functioning Means*

	Parent		Adolescent	
	Current	Future	Current	Future
ASD	2.79	3.16	3.28	3.76
Control	4.23	4.33	4.06	4.24

interaction between rater and group was significant, which reflects the fact that in the ASD group, adolescents rated their functioning higher than the parent-rated functioning, while in the control group, adolescents-rated functioning was lower than parent-rated functioning ( $F(1,50) = 20.65, p < 0.001$ ). The interaction between time and group was significant, which means that the difference between current and future functioning in the ASD group was larger than the difference between current and future functioning in the control group ( $F(1,50) = 20.25, p < 0.001$ ). The three-way interaction between rater, time period, and group was not significant ( $F(1,50) = 0.11, p = 0.74$ ).

These results show that adolescents with ASD were not completely aware of their current functioning, since they rated higher functioning than their parents endorsed, while adolescents in the control group perceived more functioning problems than their parents reported. Additionally, parents and adolescents in the ASD group were aware of the adolescents' functioning problems since they endorsed more problems than the control group. Even though all informants believed adolescents would perform better in the future, participants in the ASD group thought that adolescents with ASD would have a larger improvement in functioning than the improvement reported by participants in the control group.

## CHAPTER IV

### DISCUSSION

This study is one of only a few to examine adolescent and parent perceptions of psychological problems in adolescents with ASD (Green, Gilchrist, Burton, & Cox, 2000; Hurtig et al., 2009). It is the first to focus on the difference between adolescents' with ASD self-report and parent-report of school, home, and social functioning, and only the second study found to examine self- and parent-report on the ASEBA in adolescents with ASD. The capacity of individuals with ASD to report problems may be questioned. However, Ozonoff, Garcia, Clark, and Lainhart (2005) found that college-age adults with ASD were able to accurately report problems on the MMPI, since they reported a similar profile on the MMPI to what is known clinically about the personalities of persons with ASD. Adolescents with ASD in this study also demonstrated the ability to report their problems behaviors and rated their problems more similarly to their parents than was expected.

#### Comorbid Psychiatric Disorders

The prevalence of comorbid psychiatric diagnoses found in this study was similar to what has been described in previous research. ADHD, anxiety disorders,

mood disorders, OCD, and psychotic disorders all have been reported as occurring frequently in adolescents with ASD (Amr, Raddad, El-Mahesh, Bakr, Sallam, & Amin, 2012; Hofvander et al., 2009; Leyfer et al., 2006). This study found that anxiety disorders were most prevalent (58% of participants with ASD). Other frequent comorbid diagnoses in this study included ADHD (54%), Depression (46%), and Bipolar Disorders (35%). Other studies have found adolescents with ASD who are diagnosed with Conduct Disorder (Amr, Raddad, El-Mahesh, Bakr, Sallam, & Amin, 2012) and ODD (Levy et al., 2010); however, no adolescents in this study had either of these diagnoses. Bipolar disorders and depression were more common in this study than is reported in other studies, but the general class of mood disorders is commonly found in other studies of adolescents with ASD. The prevalence of types of comorbid psychiatric disorders in this study indicates that the adolescents with ASD in this study are comparable to those described in previous research.

The prevalence of comorbid psychiatric disorders found in this study was higher than in typical adolescents. In the general population of children aged 8-15, the 12-month prevalence of ADHD is 8.6%, mood disorders is 3.7%, depression is 2.7%, and anxiety disorders is 0.7% (Merikangas, He, Brody, Fisher, Bourdon & Koretz, 2010). Lifetime prevalence of psychiatric disorders in adolescents aged 13-18 years is anxiety disorders 31.9%, mood disorders 14.3%, depression 11.7%, ADHD is 8.7%, and Bipolar disorders 2.9% (Merikangas et al., 2010). The prevalence of comorbid psychiatric disorders for adolescents with ASD in this study was higher than the both the 12-month and lifetime prevalence rates in the general population. Higher prevalence

rates were expected since adolescents with ASD had to be diagnosed with a comorbid disorder in order to participate in the study. The high prevalence rates show that many psychiatric disorders were present in the adolescents with ASD who participated in this study.

Parents were shown to be accurate reporters of psychological problems since reported comorbid psychiatric diagnoses matched parent scores on the ASEBA. Fifty-eight percent of adolescents with ASD had an anxiety disorder diagnosis and their parents rated 58% of them with clinical scores on the Anxious/Depressed scale. Additionally, 46% of the adolescents had a diagnosis of depression and 50% of them received scores in the clinical range on the parent-report. ADHD had less of a match with parent ratings since 54% of adolescents were diagnosed with ADHD and only 31% had scores in the clinical range on Attention Problems. The match between previous diagnosis and parent-report of problems demonstrated that parents were a reliable source of information about their children's problems.

Adolescents with ASD had less of a match between their previous diagnoses and scales in the clinical range on the ASEBA. Thirty-five percent of adolescents had clinical scores on the Anxious/Depressed scale, which is somewhat less than the number that had anxiety disorder diagnoses (58%). Depression was more accurate as 31% had clinical scores on the Withdrawn/Depressed scale and 46% had depression diagnoses. Report of Attention Problems was not accurate as 12% of adolescents with ASD had scores in the clinical range while 54% had diagnoses of ADHD. This indicates that adolescents with ASD may be better able to report internalizing symptoms than



symptoms in other categories. However, they were still able to report psychological problems that corresponded to previous psychiatric diagnoses.

### Awareness of Problems

Examination of the self-report of psychological problems and everyday functioning of adolescents with ASD reveals that these individuals were not completely aware of their problems. On every scale of the ASEBA Child Behavior Checklist and Youth Self Report, adolescents with ASD had lower scores than their parents. Differences between parents and adolescents were significant for every scale except Somatic Complaints. The differences indicate that adolescents with ASD demonstrated a lack of full awareness of their problems in all areas except for somatic problems. Awareness of somatic symptoms was likely due to the fact that it would be difficult to be unaware of the physical discomfort these problems cause. Adolescents with ASD also lacked full self-awareness of their functioning, as they indicated that it was significantly better than the parent-report in all areas on the Rating of Functioning.

This underreporting of problems was similar to adolescents with delinquent behavior. Previous research has found that delinquent adolescents under-report psychological problems in all areas compared to their parents. Delinquent adolescents' ratings on the ASEBA were similar to the general population while their parents rated them as having the same amount of psychological problems as a clinical population on every scale of the ASEBA (Breuk, Clauser, Stams, Slot, & Doreleijers, 2007). This

demonstrates that under-reporting of problems may not be unique to adolescents with ASD and may appear in adolescents with other behavioral or psychological problems.

Adolescents in the control group did not demonstrate any deficits in self-awareness. In the control group, the only significant differences were between self- and parent-report on the Social Problems scale of the ASEBA. In Hurtig et al. (2009), adolescents in the control group also endorsed more symptoms of problem behaviors than their parents reported on the ASEBA. Additionally, adolescents in the control group reported more symptoms of social problems and a lower level of functioning than their parents. These results suggest that typically developing adolescents may often report more problems than their parents perceive, while adolescents with ASD may not accurately perceive their psychological, behavioral, and functioning problems.

The lack of self-awareness of adolescents with ASD in this study is contrary to what was found in Hurtig et al. (2009). In that sample population, there were strong positive correlations between adolescent and parent scores on the Somatic Complaints, Social Problems, Delinquent Behavior, Aggressive Behavior, and Externalizing ASEBA scales for the ASD group. Additionally, adolescents with ASD endorsed more symptoms than their parents reported on the Anxious/Depressed, Thought Problems, and Total scales in Hurtig et al. (2009). Those results contradict what was found in this study.

The differing results may be due to the populations sampled. Hurtig and her colleagues recruited participants from a previous epidemiological study and from an outpatient clinic, while the majority of adolescents in this study had previously received

inpatient psychiatric treatment. Thus, the participants in this study may have had more severe psychiatric problems than the adolescents in Hurtig et al. (2009). Hurtig and her colleagues did not report rates of comorbid psychiatric diagnoses or mean *T*-scores on the ASEBA so it is not possible to compare the populations sampled on those factors. It was reported that on the Total, 26.1% of self-report and 54.3% of parent-report scores were in the clinical range. This is compared to 35% of self-report and 58% of parent-report Total scores in the clinical range for this study. The percentage of clinical Total scores is higher in this study, but the difference is not large. It is not possible to determine which psychological problems elevated the Total score in Hurtig et al. (2009) due to the necessary data not being reported. Therefore, it is not certain what differences between Hurtig et al. (2009) and the current study caused the difference in results.

### Awareness of Psychological Problems

Findings of this study indicate that adolescents with ASD were not fully aware of all problems related to their psychiatric disorders. All adolescents with ASD were diagnosed with at least one comorbid psychiatric disorder that corresponded to scales on the ASEBA. If they had demonstrated awareness of problems due to these disorders, then ASEBA mean scale scores should have been elevated into the clinical range. This was not the case, as no mean self-report scales of adolescents with ASD were in the clinical range. Therefore, many of these individuals did not perceive their problems to be clinically significant, even though they were currently receiving or had previously received treatment for these problems.

However, adolescents with ASD were able to report some psychological and behavior problems. On the self-report of the ASEBA, the mean score on the Anxious/Depressed scale was in the borderline clinical range, and mean scores were elevated at least one standard deviation on all other scales for the ASD group. Anxiety disorders were the most common comorbid diagnoses in this study, so the elevation on Anxious/Depressed suggests some awareness of problems due to anxiety. Elevations on the other scales show that adolescents with ASD were aware of some symptoms of other psychological and behavior problems as well. Furthermore, the difference between parent and adolescent report on the ASEBA was only half of a standard deviation on most scales. This shows that even though there were significant differences, the differences were not large in terms of the scale used. Therefore, even though adolescents with ASD demonstrated some deficits in self-awareness, they were aware of psychological problems, including anxiety and depression, and able to report these problems.

#### Awareness of Functioning

Adolescents with ASD also were not fully aware of their everyday functioning. Parent-report of problems, lower GPA than the control group, lack of friends, and a high rate of utilization of special education services all indicate that these adolescents had functioning problems. However, adolescents with ASD reported more functional behaviors than their parents endorsed on all areas of the Rating of Functioning. Over-

reporting of functional behaviors indicates that they were unaware of some of their problems in this area.

However, adolescents with ASD did not demonstrate a complete lack of awareness of their functioning. Adolescents reported their functioning in different areas with the same rank order as their parents (best functioning at school, then home, and then social). This suggests that they were able to see the areas where they perform best and worst, even if they did not perceive the full degree of their problems. Additionally, adolescents with ASD reported lower functioning than adolescents in the control group in all areas of current functioning. Reporting lower functioning shows that adolescents with ASD were aware of some of their deficits in functioning. Furthermore, even though the differences between scores were statistically significant, adolescents with ASD rated their functioning in the same nominal category as their parents in current school and social functioning (both rated functional behaviors as occurring “Sometimes” at school and “Infrequently” socially). These findings indicate that even though adolescents with ASD demonstrated a lack of self-awareness, they were aware of some of their deficits in functioning and able to report problems in the same areas as their parents.

Like their parents, adolescents in both groups predicted that their functioning would improve in 6 months. However, adolescents with ASD reported that they would do better in the future than their parents predicted, while the predictions of adolescents in the control group were lower than their parents’ predictions. Adolescents with ASD even predicted that their social functioning would be higher than the social functioning

of adolescents in the control group. It is interesting that everyone believed that the adolescents would have higher functioning only 6 months in the future. Adolescents ranged in age from 11-18 years so parents should have had enough previous experience to not have unrealistic expectations for their children. A few parents of adolescents with ASD mentioned during the interview that their child had done better since being hospitalized, so it is possible that parents believed hospitalization had successfully treated their children's problems, and as a result functioning would improve. It also possibly represents that optimism for the future and believing that the adolescents will perform better in the future is just part of a healthy outlook on life.

### Implications for Practice

#### Onset and Course of Treatment

Psychiatric problems started in childhood for adolescents with ASD. On average, onset of problems occurred when participants were 9 years of age, although onset was earlier for those diagnosed with Autistic Disorder and later for individuals diagnosed with PDD-NOS. It took about 2 years from problem onset for participants to receive their first outpatient treatment. After that, it was a further 2 years before first admittance to psychiatric inpatient treatment. The delay in receiving initial treatment indicates that parents of children with ASD may have attempted to handle problems on their own before seeking help. Parents then utilized outpatient treatment before inpatient treatment. This service pattern shows that parents used less intensive treatment before resorting to hospitalization.

The adolescents with ASD in this study received a variety of treatments for their psychiatric problems. However, they still had significant externalizing behaviors. A majority of the adolescents with ASD were verbally or physically aggressive, had threatened or attempted suicide, and had previously received inpatient psychiatric treatment. Half of the adolescents with ASD in the study were admitted to inpatient treatment for aggression towards themselves or others. However, results of the ASEBA indicated that internalizing problems were more severe than externalizing problems. This suggests that aggression in these adolescents may represent frustration and an inability to deal with their problems. Failure to handle their problems without extreme frustration and aggression may indicate that previous treatments have not improved psychiatric symptoms of ASD and comorbid disorders.

### Implications for Treatment

Adolescents with ASD had significant psychiatric symptoms even though they had received outpatient, inpatient, and pharmacological treatment. This indicates that their current psychiatric treatments were not effective. Additionally, inpatient treatment did not necessarily lead to long-term improvement since the adolescents had, on average, two inpatient treatments and many had more. This suggests that more continuing services are needed for adolescents with ASD who have comorbid psychiatric disorders. Adolescents who end up in inpatient treatment may need continued follow-up and management after they are discharged from the hospital. This study indicates that treating for crises and then releasing does not work with this

population since, 10 months after their last inpatient visit, adolescents still had significant psychological problems. Long-term follow-up is needed to continue to support adolescents with ASD and their families.

Adolescents' deficits in self-awareness also need to be acknowledged in treatment. It is likely impossible to change adolescents' perceptions to allow them to perceive things in the same way as others. However, knowing that they do not perceive problems can help clinicians plan treatment. It also increases the importance of obtaining adolescent's perceptions of their problems rather than relying on parent-report alone. Providers need to help adolescents with ASD learn to manage their problems and be aware of how they perceive their problems.

This study's findings show that both adolescents and their parents predict that adolescents' functioning will improve in the future. Optimism about the future can be used to help adolescents with ASD set goals and focus on what they can change to be able to function the way that they predict. Additionally, adolescents' optimism can be used to help motivate them during treatment, and help adolescents and their parents work towards better functioning in the future. Finally, treatment providers can work to help adolescents with ASD reach the level of functioning that they and their parents believe is possible.

### Limitations

One limitation of this study is that only self- and parent-report were examined, and no information was included from participants' teachers. Teacher reports would



have given more information about problems at school. Additionally, only a single measure of psychological problems (the ASEBA) was used, and a structured psychiatric interview, such as the KSADS, was not included. Therefore, results may not be comparable to other measures of psychological problems. Furthermore, the Rating of Functioning is an investigator-generated measure created for this study. Some of its items came from behavioral checklists with acceptable reliability and validity; however, there are no psychometric properties available for the Rating of Functioning. Additionally, no test-retest reliability was assessed for this measure. Therefore, even though it has face validity, it cannot be determined whether the Rating of Functioning is reliable and valid.

Another limitation is the analysis for Hypothesis 6. This analysis relied on a difference score (parent-report subtracted from self-report on the Rating of Functioning) to examine the hypothesis, and difference scores are inherently unreliable. Also, the analysis involved correlating the parent-report CBCL to the difference score. Since the difference score was partially based on the parent-report on the Rating of Functioning, it is likely that the two measures would be correlated because the same rater was involved in both scores. Therefore, the results of the analysis for Hypothesis 6 should be interpreted with caution.

Other limitations are related to the sample. Only adolescents with ASD who had comorbid psychiatric diagnoses were included in this study, and the majority had previously received inpatient psychiatric treatment, including medication. Therefore, results may not apply to adolescents with ASD who have less severe psychiatric

symptoms or who have not received treatment. Furthermore, all participants had an IQ of 85 or higher so results may not apply to individuals with lower cognitive ability, including those with borderline IQ. The study also only included males so results may not be applicable to females. Finally, there were only 26 adolescents in each group. This limits generalization to other samples of adolescents with ASD. A larger sample size would have represented the general population better and enabled more comparisons and generalization of results.

### Future Research

More research is needed on comorbid psychiatric disorders in adolescents with ASD. This population may benefit from more research that examines the reliability and validity of self-report. Most current research focuses on parent-reports of problem behaviors. Interviewing adolescents and asking them about their concerns and problems they feel are important could improve our understanding of this population. Results from this study indicate that many adolescents with ASD who have comorbid disorders have aggression and other problems that may be difficult for families to manage. Therefore, there may be benefit from research that examines how psychiatric and behavioral problems relate to family stress. Additionally, examining psychiatric symptoms in the broader population of individuals with ASD, who have less severe psychiatric symptoms, may provide further insights into how psychiatric problems develop in these adolescents. More information about the severity of ASD symptoms and how they may be related to psychiatric disorders could inform treatment. Females

with ASD and comorbid psychiatric disorders may differ from males in their psychiatric symptoms and awareness of their problems so these differences need to be examined. Finally, the optimism about future everyday functioning could be further examined to determine why parents and adolescents are optimistic and whether they believe other behaviors will improve.

### Summary

Participants with ASD reported significantly fewer problem behaviors than their parents reported; however, they reported more problems than typical adolescents, and were able to report psychological and functioning problems. Even after multiple psychiatric treatments, medications, and follow-up care, adolescents with ASD still report problems. However, both adolescents and parents were optimistic about adolescents' performance in the future. Delays in treatment need to be addressed and long-term follow-up care is needed to support adolescents and their families while they are still optimistic about the future.

## APPENDIX A

### ASD AND CONTROL FLYERS

## **We Need Adolescents and Their Parents For a Study at the University of Utah**

**We are studying how adolescents with an autism spectrum disorder view their problems compared to how their parents view their problems.**

**Participants needed are males:**

- Ages 11-18
- Living with a biological parent who is willing to participate in the study
- Diagnosed with an autism spectrum disorder (autism, Asperger's, PDD)
- Have other psychological problems
- Read at 6<sup>th</sup> grade level or above and no serious cognitive delays

**Participation in the study requires:**

- A brief IQ, reading test, and autism assessment for the adolescent
- Completion of behavior rating forms by the adolescent and parent
- Completion of a developmental questionnaire and interview by the parent

**Participants benefit by:**

- Will receive a written summary of the results of testing
- Contributing to a better understanding of how adolescents with autism spectrum disorders view their problems

### **PLEASE SHARE WITH OTHERS**

If you are not interested but know someone who might be  
please have them contact us.

**For more information call (801)-618-9095**

Ask for Will Backner. Please leave a message.

## **We Need Teens and Their Parents For a Study at the University of Utah**

**We are studying how teenagers view themselves compared to how their parents view their children.**

**To be in the study you need to:**

- Be a male ages 11-18
- Be living with a parent who can be in the study and speaks English
- Read at the 6<sup>th</sup> grade level or above
- Have average intellectual ability
- Have never had mental health problems
- Not have a diagnosis of autism, Asperger's, or PDD

**The study involves:**

- The teenager will do three brief tests (vocabulary, reading, and picture puzzles)
- The teenager and parent will fill out two surveys each
- The parent will do a short interview about their child
- The study can take place at the University of Utah or anywhere else (interviewer can travel to you).

**You benefit by:**

- Helping us understand how teenagers view their problems
- Receiving a free report of the results of your testing (IQ, reading level, and behavior ratings)
- Teenagers will receive \$10 for being in the study

### **PLEASE SHARE WITH OTHERS**

If you are not interested but know someone who might be  
please have them contact us.

**For more information call (801)-618-9095**

Ask for Will Backner. Please leave a message.

## APPENDIX B

### ASD GROUP: ADULT CONSENT, PARENT PERMISSION, AND ADOLESCENT ASSENT FORMS

## Consent Document

### BACKGROUND

You are being asked to take part in a research study. Before you decide it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully. Ask us if there is anything that is not clear or if you would like more information. Take time to decide whether you want to volunteer to take part in this study.

The purpose of the study is to investigate psychological problems in adolescents with an autism spectrum disorder (ASD) who also have a diagnosed psychiatric disorder. The study will compare parent perceptions of problem behaviors to adolescent perceptions of problem behaviors in adolescents with an ASD and in typical adolescents.

This research is being done because adolescents with ASDs often experience psychological problems other than those directly related to autism. It is important to understand the additional problems that these adolescents face in order to better help them. Understanding the way that an adolescent's perceptions of problems compare to the perceptions of his parent may lead to important areas to focus on when providing treatment to adolescents with ASD.

This study is being conducted by William Backner, a graduate student in the School Psychology program in the Department of Educational Psychology at the University of Utah, and his supervisors who are faculty members of the University of Utah. The study is being conducted as part of dissertation research for William Backner.

### STUDY PROCEDURE

#### If you are a parent of a participant:

It will take you approximately 1 hour to complete this study. You will be asked to participate in an interview about your child that will take 30 minutes or less, complete rating forms about your child's behavior, and complete a questionnaire about your child's developmental history. Completing the rating forms and questionnaire will take approximately 30 minutes. The interview consists of questions about your child's developmental and psychiatric history. The developmental questionnaire consists of questions about your child's developmental history. The rating forms you will be asked to complete are parent versions of two forms your child will complete. One form asks questions mostly about thoughts and behaviors. The other form is newly created for this study and is considered experimental because it has not been used before. It asks questions mostly about everyday behaviors.

#### If you are an 18 year old participant:

It will take you approximately 1 hour and 15 minutes to complete this study. Forty-five minutes will consist of tests that the researcher gives to you, and 30 minutes will consist of rating forms that you fill out. The tests given to you by the researcher will be discussed first. As part of this study you will be given a brief IQ test. The IQ test includes vocabulary questions and questions where you will have to choose the right answer to complete a pattern. You will also be given a brief test of reading skill. For the reading test you will be asked to read a list of words.



Additionally, you may participate in an assessment where you are asked to talk about friends, feelings, and interact with the researcher.

You will also be asked to fill out two rating forms as part of this study. One rating form asks questions mostly about thoughts and behaviors. The other rating form is newly created for this study and is considered experimental because it has not been used before. It asks questions mostly about everyday behaviors.

### **RISKS**

The risks of this study are minimal. You may feel upset thinking about or talking about personal information related to your or your child's thoughts, feelings and actions. Some of the statements on the rating forms are personal and may cause you or your child embarrassment when thinking about them. Some of the items are about psychological symptoms and may seem unusual if you have not experienced them. Additionally, if you are an adult participant you may experience frustration during the tests if are unable to answer items. These risks are similar to those experienced when discussing personal information with others and taking tests at school. If you feel upset from this experience, you can tell the researcher, and he/she will tell you about resources available to help.

### **BENEFITS**

If you take part in this study you may request a summary of the results of the tests and the forms completed by the parent and child participating in this study.

Other than that listed above, there are no direct benefits for taking part in this study. However, we hope the information we get from this study may help develop a greater understanding of how psychological problems affect adolescents with autism spectrum disorders in the future.

### **CONFIDENTIALITY**

Your data will be kept confidential. Data and records will be stored in a locked filing cabinet and on a password protected computer located in the researcher's work space. Only the researcher and members of his study team will have access to this information. Your name will be kept on the forms with your responses from any forms you fill out or any tests in which you take part. For data analysis and in publications your name will be removed and you will not be identified.

However, if you discloses actual or suspected abuse, neglect, or exploitation of a child, or disabled or elderly adult, the researcher or any member of the study staff must, and will, report this to Child Protective Services (CPS), Adult Protective Services (APS) or the nearest law enforcement agency.

There are some cases in which a researcher is obligated to report issues, such as serious threats to public health or safety. If you discloses information about harming others or themselves (i.e. suicide) the researcher or any member of the study staff must, and will, report this to the person at whom the intent to harm is directed, and any necessary agencies needed to protect that person.

William Backner  
Investigation of the Presence and Awareness of Psychological Problems  
of Male Adolescents With Autism Spectrum Disorders Who Have Been  
Treated for Psychiatric Disorders

Page 3 of 3

### PERSON TO CONTACT

If you have questions, complaints or concerns about this study, you can contact William Backner at 801-618-9095 during normal business hours. Additionally, you may contact Elaine Clark at 801-581-7148 during normal business hours.

If you feel you or your child have been harmed as a result of participation, please contact the Institutional Review Board at 801-581-3655, which may be reached at during normal business hours.

**Institutional Review Board:** Contact the Institutional Review Board (IRB) if you have questions regarding your rights as a research participant. Also, contact the IRB if you have questions, complaints or concerns which you do not feel you can discuss with the investigator. The University of Utah IRB may be reached by phone at (801) 581-3655 or by e-mail at [irb@hsc.utah.edu](mailto:irb@hsc.utah.edu).

**Research Participant Advocate:** You may also contact the Research Participant Advocate (RPA) by phone at (801) 581-3803 or by email at [participant.advocate@hsc.utah.edu](mailto:participant.advocate@hsc.utah.edu).

### VOLUNTARY PARTICIPATION

It is up to you to decide whether to take part in this study. Refusal to participate or the decision to withdraw from this research will involve no penalty or loss of benefits to which you are otherwise entitled. This will not affect your relationship with the investigator.

### COSTS AND COMPENSATION TO PARTICIPANTS

There are no costs for participation in this research. Additionally, there will be no compensation for participation in the study other than the benefits listed above.

### CONSENT

By signing this consent form, I confirm I have read the information in this consent form and have had the opportunity to ask questions. I will be given a signed copy of this consent form. I voluntarily agree to take part in this study.

\_\_\_\_\_  
Printed Name of Participant

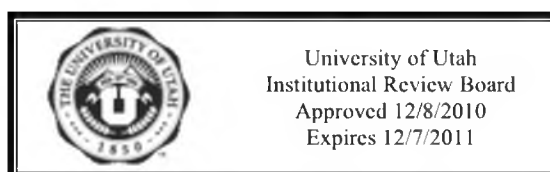
\_\_\_\_\_  
Signature of Participant

\_\_\_\_\_  
Date

\_\_\_\_\_  
Printed Name of Researcher or Staff

\_\_\_\_\_  
Signature of Researcher or Staff

\_\_\_\_\_  
Date



## Parental Permission Document

### BACKGROUND

Your child is being asked to take part in a research study. Before you decide, it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully. Ask us if there is anything that is not clear or if you would like more information. Take time to decide whether you will allow your child to take part in this study.

The purpose of the study is to investigate psychological problems in adolescents with an autism spectrum disorder (ASD) who also have a diagnosed psychiatric disorder. The study will compare parent perceptions of problem behaviors to adolescent perceptions of problem behaviors in adolescents with an ASD and in typical adolescents.

This research is being done because adolescents with ASDs often experience psychological problems other than those directly related to autism. Understanding the way that an adolescent's perceptions of problems compare to the perceptions of his parent may lead to important areas to focus on when providing treatment to adolescents with ASD.

This study is being conducted by William Backner, a graduate student in the School Psychology program in the Department of Educational Psychology at the University of Utah, and his supervisors who are faculty members of the University of Utah. The study is being conducted as part of dissertation research for William Backner.

### STUDY PROCEDURE

It will take your child approximately 1 hour and 15 minutes to complete this study. Forty-five minutes will consist of tests that the researcher gives to your child, and 30 minutes will consist of rating forms that your child fills out. Additionally, as a parent you will be asked to participate in an interview about your child that will take 30 minutes or less, complete rating forms about your child's behavior, and complete a questionnaire about your child's developmental history. Completing the rating forms and questionnaire will take approximately 30 minutes.

As part of this study your child will participate in tests that a researcher gives to them, and your child will fill out rating forms. Your child will be given a brief IQ test, which includes vocabulary questions and questions where your child will have to choose the right answer to complete a pattern. Your child will also be given a brief test of reading skill. Additionally, your child will participate in an assessment where he/she is asked to talk about friends, feelings, and interact with the researcher.

Your child will be asked to fill out two rating forms as part of this study. Both forms ask questions about feelings, actions, and thoughts. One rating form asks questions mostly about thoughts and behaviors. The other rating form is newly created for this study and is considered experimental because it has not been used before. It asks questions mostly about everyday behaviors.

## **RISKS**

The risks of this study are minimal. Your child may feel upset thinking about or talking about personal information related to their thoughts, feelings and actions. Some of the statements on the rating forms are personal and may cause your child embarrassment when thinking about them. Some of the items are about psychological symptoms and may seem unusual if your child has not experienced them. Additionally, your child may experience frustration during the tests if he is unable to answer items. These risks are similar to those experienced when discussing personal information with others and taking tests at school. If your child feels upset from this experience, you or your child can tell the researcher, and he/she will tell you about resources available to help.

## **BENEFITS**

If you take part in this study you may request a summary of the results of the tests your child will be given and the forms you and your child complete.

Other than that listed above, there are no direct benefits for taking part in this study. However, we hope the information we get from this study may help develop a greater understanding of how psychological problems affect adolescents with autism spectrum disorders in the future.

## **CONFIDENTIALITY**

Your child's data will be kept confidential. Data and records will be stored in a locked filing cabinet and on a password protected computer located in the researcher's work space. Only the researcher and members of his study team will have access to this information. Your child's name will be kept on the forms with your child's responses from the IQ, reading, and autism assessments. His/her name will also be kept with the rating forms he/she fills out. For data analysis and in publications your child's name will be removed and he/she will not be identified.

However, if your child discloses actual or suspected abuse, neglect, or exploitation of a child, or disabled or elderly adult, the researcher or any member of the study staff must, and will, report this to Child Protective Services (CPS), Adult Protective Services (APS) or the nearest law enforcement agency.

There are some cases in which a researcher is obligated to report issues, such as serious threats to public health or safety. If your child discloses information about harming others or themselves (i.e. suicide) the researcher or any member of the study staff must, and will, report this to you, the person at whom the intent to harm is directed, and any necessary agencies needed to protect that person.

## **PERSON TO CONTACT**

If you have questions, complaints or concerns about this study, you can contact William Backner at 801-618-9095 during normal business hours. Additionally, you may contact Elaine Clark at 801-581-7148 during normal business hours.

If you feel your child has been harmed as a result of participation, please contact the Institutional Review Board at 801-581-3655, which may be reached at during normal business hours.

William Backner  
Investigation of the Presence and Awareness of Psychological Problems  
of Male Adolescents With Autism Spectrum Disorders Who Have Been  
Treated for Psychiatric Disorders

Page 3 of 3

**Institutional Review Board:** Contact the Institutional Review Board (IRB) if you have questions regarding your child's rights as a research participant. Also, contact the IRB if you have questions, complaints or concerns which you do not feel you can discuss with the investigator. The University of Utah IRB may be reached by phone at (801) 581-3655 or by e-mail at [irb@hsc.utah.edu](mailto:irb@hsc.utah.edu).

**Research Participant Advocate:** You may also contact the Research Participant Advocate (RPA) by phone at (801) 581-3803 or by email at [participant.advocate@hsc.utah.edu](mailto:participant.advocate@hsc.utah.edu).

#### **VOLUNTARY PARTICIPATION**

It is up to you to decide whether to allow your child to take part in this study. Refusal to allow your child to participate or the decision to withdraw your child from this research will involve no penalty or loss of benefits to which your child is otherwise entitled. This will not affect your or your child's relationship with the investigator.

#### **COSTS AND COMPENSATION TO PARTICIPANTS**

There are no costs for participation in this research. Additionally, there will be no compensation for participation in the study other than the benefits listed above.

#### **CONSENT**

By signing this consent form, I confirm I have read the information in this parental permission form and have had the opportunity to ask questions. I will be given a signed copy of this parental permission form. I voluntarily agree to allow my child to take part in this study.

\_\_\_\_\_  
Child's Name

\_\_\_\_\_  
Parent/Guardian's Name

\_\_\_\_\_  
Parent/Guardian's Signature

\_\_\_\_\_  
Date

\_\_\_\_\_  
Relationship to Child

\_\_\_\_\_  
Name of Researcher or Staff

\_\_\_\_\_  
Signature of Researcher or Staff

\_\_\_\_\_  
Date

## **Assent to Participate in a Research Study**

### **Who are we and what are we doing?**

We are from the University of Utah. We would like to ask if you would be in a research study. A research study is a way to find out new information about something. This is the way we try to find out how teenagers feel about problems they are having.

### **Why are we asking you to be in this research study?**

We are asking you to be in this research study because we want to learn more about how teenagers with autism, Asperger's, and PDD view their problems. We would like to compare it to how parents view their children's problems. We also want to see how typical teenagers see themselves. We hope to learn better ways to help teenagers. We want you to be in this study because you are a teenager and we want to ask you about yourself.

### **What happens in the research study?**

If you decide to be in this research study and your parent or guardian agree, this is what will happen:

- We will ask you to complete some tests and fill out some rating forms
  - For the tests you will answer some questions about what words mean and how to finish a pattern. You will be asked to read some words. You will also answer questions about friends and feelings.
  - For the rating forms you will read sentences about thoughts, feelings, and actions and say how well they describe you.
- We will also ask your parents to answer some questions about you and fill out some forms about you.
- You will be in the study for about 1 hour 15 minutes. 45 minutes will be the tests, and 30 minutes will be the rating forms.

### **Will any part of the research study hurt you?**

There is a chance that during this research study you could feel afraid, uncomfortable, or embarrassed by the questions you are asked or read. We will try to help you feel better if this happens. You may think some of the questions are odd. This is because the tests and forms are made to ask about many types of problems that you may not have. You can stop at any time if you want to.

### **Will the research study help you or anyone else?**

We do not know for sure if being in this research study will help you. If your parent or guardian wants they can get a summary of results from the tests and forms you fill out. We do not know if that will help you. It is possible that we could learn something to help teenagers with autism, Asperger's, and PDD some day.

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Version: C3110



University of Utah  
Institutional Review Board  
Approved 12/8/2010  
Expires 12/7/2011

**Who will see the information about you?**

Only the researchers will be able to see the information about you from this research study. We may talk about the results from the tests with you and your parents.

If you tell us that you want to hurt yourself, we will tell other adults about it so that we can help you feel better.

**What if you have any questions about the research study?**

It is okay to ask questions. If you don't understand something, you can ask us. We want you to ask questions now and anytime you think of them. If you have a question later that you didn't think of now, you can call William Backner at 801-618-9095.

**Do you have to be in the research study?**

You do not have to be in this study if you don't want to. Being in this study is up to you. No one will be upset if you don't want to do it. Even if you say yes now, you can change your mind later and tell us you want to stop. We will also ask your parent or guardian to give their permission for you to be in this study. But even if your parent or guardian says "yes" you can still decide not to be in the research study.

**Agreeing to be in the study**

I was able to ask questions about this study. Signing my name at the bottom means that I agree to be in this study. My parent or guardian and I will be given a copy of this form after I have signed it.

\_\_\_\_\_  
Printed Name

\_\_\_\_\_  
Sign your name on this line

\_\_\_\_\_  
Date

\_\_\_\_\_  
Printed Name of Person Obtaining Assent

\_\_\_\_\_  
Signature of Person Obtaining Assent

\_\_\_\_\_  
Date

**For IRB Use Only**  
Version: C3110



University of Utah  
Institutional Review Board  
Approved 12/8/2010  
Expires 12/7/2011

William Backner  
Investigation of the Presence and Awareness of Psychological Problems  
of Male Adolescents With Autism Spectrum Disorders Who Have Been  
Treated for Psychiatric Disorders

Page 3 of 3

The following should be completed by the study member conducting the assent process if the participant agrees to be in the study. Initial the appropriate selection:

\_\_\_\_\_ The participant is capable of reading the assent form and has signed above as documentation of assent to take part in this study.

\_\_\_\_\_ The participant is not capable of reading the assent form, but the information was verbally explained to him/her. The participant signed above as documentation of assent to take part in this study.

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Version: C3110



University of Utah  
Institutional Review Board  
Approved 12/8/2010  
Expires 12/7/2011



## APPENDIX C

CONTROL GROUP: ADULT CONSENT, PARENT PERMISSION,  
AND ADOLESCENT ASSENT FORMS

## Consent Document

### BACKGROUND

You are being asked to take part in a research study. Before you decide it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully. Ask us if there is anything that is not clear or if you would like more information. Take time to decide whether you want to volunteer to take part in this study.

The purpose of the study is to investigate psychological problems in adolescents with an autism spectrum disorder (ASD) who also have a diagnosed psychiatric disorder. The study will compare parent perceptions of problem behaviors to adolescent perceptions of problem behaviors in adolescents with an ASD and in typical adolescents.

This research is being done because adolescents with ASDs often experience psychological problems other than those directly related to autism. It is important to understand the additional problems that these adolescents face in order to better help them. Understanding the way that an adolescent's perceptions of problems compare to the perceptions of his parent may lead to important areas to focus on when providing treatment to adolescents with ASD.

This study is being conducted by William Backner, a graduate student in the School Psychology program in the Department of Educational Psychology at the University of Utah, and his supervisors who are faculty members of the University of Utah. The study is being conducted as part of dissertation research for William Backner.

### STUDY PROCEDURE

#### If you are a parent of a participant:

It will take you approximately 1 hour to complete this study. You will be asked to participate in an interview about your child that will take 30 minutes or less, complete rating forms about your child's behavior, and complete a questionnaire about your child's developmental history. Completing the rating forms and questionnaire will take approximately 30 minutes. The interview consists of questions about your child's developmental and psychiatric history. The developmental questionnaire consists of questions about your child's developmental history. The rating forms you will be asked to complete are parent versions of two forms your child will complete. One form asks questions mostly about thoughts and behaviors. The other form is newly created for this study and is considered experimental because it has not been used before. It asks questions mostly about everyday behaviors.

#### If you are an 18 year old participant:

It will take you approximately 1 hour and 15 minutes to complete this study. Forty-five minutes will consist of tests that the researcher gives to you, and 30 minutes will consist of rating forms that you fill out. The tests given to you by the researcher will be discussed first. As part of this study you will be given a brief IQ test. The IQ test includes vocabulary questions and questions where you will have to choose the right answer to complete a pattern. You will also be given a brief test of reading skill. For the reading test you will be asked to read a list of words.

Additionally, you may participate in an assessment where you are asked to talk about friends, feelings, and interact with the researcher.

You will also be asked to fill out two rating forms as part of this study. One rating form asks questions mostly about thoughts and behaviors. The other rating form is newly created for this study and is considered experimental because it has not been used before. It asks questions mostly about everyday behaviors.

### **RISKS**

The risks of this study are minimal. You may feel upset thinking about or talking about personal information related to your or your child's thoughts, feelings and actions. Some of the statements on the rating forms are personal and may cause you or your child embarrassment when thinking about them. Some of the items are about psychological symptoms and may seem unusual if you have not experienced them. Additionally, if you are an adult participant you may experience frustration during the tests if are unable to answer items. These risks are similar to those experienced when discussing personal information with others and taking tests at school. If you feel upset from this experience, you can tell the researcher, and he/she will tell you about resources available to help.

### **BENEFITS**

If you take part in this study you may request a summary of the results of the tests and the forms completed by the parent and child participating in this study. Other than that listed above, there are no direct benefits for taking part in this study. However, we hope the information we get from this study may help develop a greater understanding of how psychological problems affect adolescents with autism spectrum disorders in the future.

### **CONFIDENTIALITY**

Your data will be kept confidential. Data and records will be stored in a locked filing cabinet and on a password protected computer located in the researcher's work space. Only the researcher and members of his study team will have access to this information. Your name will be kept on the forms with your responses from any forms you fill out or any tests in which you take part. For data analysis and in publications your name will be removed and you will not be identified.

However, if you discloses actual or suspected abuse, neglect, or exploitation of a child, or disabled or elderly adult, the researcher or any member of the study staff must, and will, report this to Child Protective Services (CPS), Adult Protective Services (APS) or the nearest law enforcement agency.

There are some cases in which a researcher is obligated to report issues, such as serious threats to public health or safety. If you discloses information about harming others or themselves (i.e. suicide) the researcher or any member of the study staff must, and will, report this to the person at whom the intent to harm is directed, and any necessary agencies needed to protect that person.

William Backner  
Investigation of the Presence and Awareness of Psychological Problems  
of Male Adolescents With Autism Spectrum Disorders Who Have Been  
Treated for Psychiatric Disorders

Page 3 of 3

### PERSON TO CONTACT

If you have questions, complaints or concerns about this study, you can contact William Backner at 801-618-9095 during normal business hours. Additionally, you may contact Elaine Clark at 801-581-7148 during normal business hours.

If you feel you or your child have been harmed as a result of participation, please contact the Institutional Review Board at 801-581-3655, which may be reached at during normal business hours.

**Institutional Review Board:** Contact the Institutional Review Board (IRB) if you have questions regarding your rights as a research participant. Also, contact the IRB if you have questions, complaints or concerns which you do not feel you can discuss with the investigator. The University of Utah IRB may be reached by phone at (801) 581-3655 or by e-mail at [irb@hsc.utah.edu](mailto:irb@hsc.utah.edu).

**Research Participant Advocate:** You may also contact the Research Participant Advocate (RPA) by phone at (801) 581-3803 or by email at [participant.advocate@hsc.utah.edu](mailto:participant.advocate@hsc.utah.edu).

### VOLUNTARY PARTICIPATION

It is up to you to decide whether to take part in this study. Refusal to participate or the decision to withdraw from this research will involve no penalty or loss of benefits to which you are otherwise entitled. This will not affect your relationship with the investigator.

### COSTS AND COMPENSATION TO PARTICIPANTS

There are no costs for participation in this research. If you are the adolescent participating in the study then you will receive \$10 an hour for your participation. Since it takes about an hour for the adolescent to complete the study, he will receive \$10.

### CONSENT

By signing this consent form, I confirm I have read the information in this consent form and have had the opportunity to ask questions. I will be given a signed copy of this consent form. I voluntarily agree to take part in this study.

\_\_\_\_\_  
Printed Name of Participant

\_\_\_\_\_  
Signature of Participant

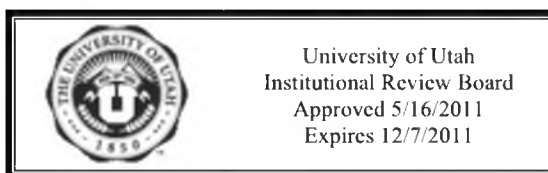
\_\_\_\_\_  
Date

\_\_\_\_\_  
Printed Name of Researcher or Staff

\_\_\_\_\_  
Signature of Researcher or Staff

\_\_\_\_\_  
Date

FOOTER FOR IRB USE ONLY  
Version: B1209



## Parental Permission Document

### BACKGROUND

Your child is being asked to take part in a research study. Before you decide, it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully. Ask us if there is anything that is not clear or if you would like more information. Take time to decide whether you will allow your child to take part in this study.

The purpose of the study is to investigate psychological problems in adolescents with an autism spectrum disorder (ASD) who also have a diagnosed psychiatric disorder. The study will compare parent perceptions of problem behaviors to adolescent perceptions of problem behaviors in adolescents with an ASD and in typical adolescents.

This research is being done because adolescents with ASDs often experience psychological problems other than those directly related to autism. Understanding the way that an adolescent's perceptions of problems compare to the perceptions of his parent may lead to important areas to focus on when providing treatment to adolescents with ASD.

This study is being conducted by William Backner, a graduate student in the School Psychology program in the Department of Educational Psychology at the University of Utah, and his supervisors who are faculty members of the University of Utah. The study is being conducted as part of dissertation research for William Backner.

### STUDY PROCEDURE

It will take your child approximately 1 hour and 15 minutes to complete this study. Forty-five minutes will consist of tests that the researcher gives to your child, and 30 minutes will consist of rating forms that your child fills out. Additionally, as a parent you will be asked to participate in an interview about your child that will take 30 minutes or less, complete rating forms about your child's behavior, and complete a questionnaire about your child's developmental history. Completing the rating forms and questionnaire will take approximately 30 minutes.

As part of this study your child will participate in tests that a researcher gives to them, and your child will fill out rating forms. Your child will be given a brief IQ test, which includes vocabulary questions and questions where your child will have to choose the right answer to complete a pattern. Your child will also be given a brief test of reading skill. Additionally, your child will participate in an assessment where he/she is asked to talk about friends, feelings, and interact with the researcher.

Your child will be asked to fill out two rating forms as part of this study. Both forms ask questions about feelings, actions, and thoughts. One rating form asks questions mostly about thoughts and behaviors. The other rating form is newly created for this study and is considered experimental because it has not been used before. It asks questions mostly about everyday behaviors.

## **RISKS**

The risks of this study are minimal. Your child may feel upset thinking about or talking about personal information related to their thoughts, feelings and actions. Some of the statements on the rating forms are personal and may cause your child embarrassment when thinking about them. Some of the items are about psychological symptoms and may seem unusual if your child has not experienced them. Additionally, your child may experience frustration during the tests if he is unable to answer items. These risks are similar to those experienced when discussing personal information with others and taking tests at school. If your child feels upset from this experience, you or your child can tell the researcher, and he/she will tell you about resources available to help.

## **BENEFITS**

If you take part in this study you may request a summary of the results of the tests your child will be given and the forms you and your child complete. Other than that listed above, there are no direct benefits for taking part in this study. However, we hope the information we get from this study may help develop a greater understanding of how psychological problems affect adolescents with autism spectrum disorders in the future.

## **CONFIDENTIALITY**

Your child's data will be kept confidential. Data and records will be stored in a locked filing cabinet and on a password protected computer located in the researcher's work space. Only the researcher and members of his study team will have access to this information. Your child's name will be kept on the forms with your child's responses from the IQ, reading, and autism assessments. His/her name will also be kept with the rating forms he/she fills out. For data analysis and in publications your child's name will be removed and he/she will not be identified.

However, if your child discloses actual or suspected abuse, neglect, or exploitation of a child, or disabled or elderly adult, the researcher or any member of the study staff must, and will, report this to Child Protective Services (CPS), Adult Protective Services (APS) or the nearest law enforcement agency.

There are some cases in which a researcher is obligated to report issues, such as serious threats to public health or safety. If your child discloses information about harming others or themselves (i.e. suicide) the researcher or any member of the study staff must, and will, report this to you, the person at whom the intent to harm is directed, and any necessary agencies needed to protect that person.

## **PERSON TO CONTACT**

If you have questions, complaints or concerns about this study, you can contact William Backner at 801-618-9095 during normal business hours. Additionally, you may contact Elaine Clark at 801-581-7148 during normal business hours.

If you feel your child has been harmed as a result of participation, please contact the Institutional Review Board at 801-581-3655, which may be reached at during normal business hours.

William Backner  
Investigation of the Presence and Awareness of Psychological Problems  
of Male Adolescents With Autism Spectrum Disorders Who Have Been  
Treated for Psychiatric Disorders

Page 3 of 3

**Institutional Review Board:** Contact the Institutional Review Board (IRB) if you have questions regarding your child's rights as a research participant. Also, contact the IRB if you have questions, complaints or concerns which you do not feel you can discuss with the investigator. The University of Utah IRB may be reached by phone at (801) 581-3655 or by e-mail at [irb@hsc.utah.edu](mailto:irb@hsc.utah.edu).

**Research Participant Advocate:** You may also contact the Research Participant Advocate (RPA) by phone at (801) 581-3803 or by email at [participant.advocate@hsc.utah.edu](mailto:participant.advocate@hsc.utah.edu).

#### **VOLUNTARY PARTICIPATION**

It is up to you to decide whether to allow your child to take part in this study. Refusal to allow your child to participate or the decision to withdraw your child from this research will involve no penalty or loss of benefits to which your child is otherwise entitled. This will not affect your or your child's relationship with the investigator.

#### **COSTS AND COMPENSATION TO PARTICIPANTS**

There are no costs for participation in this research. Your child will receive \$10 an hour for completing the study. Since it takes about an hour for study completion your child will receive \$10.

#### **CONSENT**

By signing this consent form, I confirm I have read the information in this parental permission form and have had the opportunity to ask questions. I will be given a signed copy of this parental permission form. I voluntarily agree to allow my child to take part in this study.

\_\_\_\_\_  
Child's Name

\_\_\_\_\_  
Parent/Guardian's Name

\_\_\_\_\_  
Parent/Guardian's Signature

\_\_\_\_\_  
Date

\_\_\_\_\_  
Relationship to Child

\_\_\_\_\_  
Name of Researcher or Staff

\_\_\_\_\_  
Signature of Researcher or Staff

\_\_\_\_\_  
Date

## **Assent to Participate in a Research Study**

### **Who are we and what are we doing?**

We are from the University of Utah. We would like to ask if you would be in a research study. A research study is a way to find out new information about something. This is the way we try to find out how teenagers feel about problems they are having.

### **Why are we asking you to be in this research study?**

We are asking you to be in this research study because we want to learn more about how teenagers with autism, Asperger's, and PDD view their problems. We would like to compare it to how parents view their children's problems. We also want to see how typical teenagers see themselves. We hope to learn better ways to help teenagers. We want you to be in this study because you are a teenager and we want to ask you about yourself.

### **What happens in the research study?**

If you decide to be in this research study and your parent or guardian agree, this is what will happen:

- We will ask you to complete some tests and fill out some rating forms
  - For the tests you will answer some questions about what words mean and how to finish a pattern. You will be asked to read some words. You will also answer questions about friends and feelings.
  - For the rating forms you will read sentences about thoughts, feelings, and actions and say how well they describe you.
- We will also ask your parents to answer some questions about you and fill out some forms about you.
- You will be in the study for about 1 hour 15 minutes. 45 minutes will be the tests, and 30 minutes will be the rating forms.

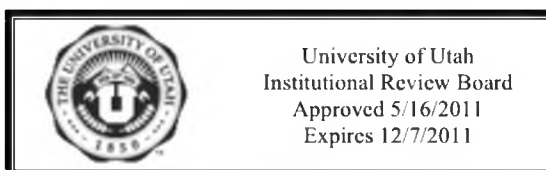
### **Will any part of the research study hurt you?**

There is a chance that during this research study you could feel afraid, uncomfortable, or embarrassed by the questions you are asked or read. We will try to help you feel better if this happens. You may think some of the questions are odd. This is because the tests and forms are made to ask about many types of problems that you may not have. You can stop at any time if you want to.

### **Will the research study help you or anyone else?**

We do not know for sure if being in this research study will help you. If your parent or guardian wants they can get a summary of results from the tests and forms you fill out. We do not know if that will help you. It is possible that we could learn something to help teenagers with autism, Asperger's, and PDD some day.

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William Backner  
Investigation of the Presence and Awareness of Psychological Problems  
of Male Adolescents With Autism Spectrum Disorders Who Have Been  
Treated for Psychiatric Disorders

Page 2 of 3

Additionally, you will receive \$10 an hour for participating in this study. Since it takes about an hour to complete the study you will receive \$10.

**Who will see the information about you?**

Only the researchers will be able to see the information about you from this research study. We may talk about the results from the tests with you and your parents.

If you tell us that you want to hurt yourself, we will tell other adults about it so that we can help you feel better.

**What if you have any questions about the research study?**

It is okay to ask questions. If you don't understand something, you can ask us. We want you to ask questions now and anytime you think of them. If you have a question later that you didn't think of now, you can call William Backner at 801-618-9095.

**Do you have to be in the research study?**

You do not have to be in this study if you don't want to. Being in this study is up to you. No one will be upset if you don't want to do it. Even if you say yes now, you can change your mind later and tell us you want to stop. We will also ask your parent or guardian to give their permission for you to be in this study. But even if your parent or guardian says "yes" you can still decide not to be in the research study.

**Agreeing to be in the study**

I was able to ask questions about this study. Signing my name at the bottom means that I agree to be in this study. My parent or guardian and I will be given a copy of this form after I have signed it.

\_\_\_\_\_  
Printed Name

\_\_\_\_\_  
Sign your name on this line

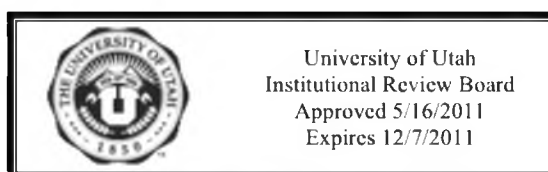
\_\_\_\_\_  
Date

\_\_\_\_\_  
Printed Name of Person Obtaining Assent

\_\_\_\_\_  
Signature of Person Obtaining Assent

\_\_\_\_\_  
Date

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William Backner  
Investigation of the Presence and Awareness of Psychological Problems  
of Male Adolescents With Autism Spectrum Disorders Who Have Been  
Treated for Psychiatric Disorders

Page 3 of 3

The following should be completed by the study member conducting the assent process if the participant agrees to be in the study. Initial the appropriate selection:

\_\_\_\_\_ The participant is capable of reading the assent form and has signed above as documentation of assent to take part in this study.

\_\_\_\_\_ The participant is not capable of reading the assent form, but the information was verbally explained to him/her. The participant signed above as documentation of assent to take part in this study.

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Version: C3110



University of Utah  
Institutional Review Board  
Approved 5/16/2011  
Expires 12/7/2011

## APPENDIX D

### RATING OF FUNCTIONING: ADOLESCENT AND PARENT FORMS

Name: \_\_\_\_\_

ID#: \_\_\_\_\_

### Adolescent Questionnaire

Please read the following sentences and rate how often they apply to you. Circle the number that that most closely matches how often you fit the statement. If you don't know about an item give your best guess. For the items that rate where you are now, think about events that have occurred over the past 2 weeks.

Name: \_\_\_\_\_

ID#: \_\_\_\_\_

## Adolescent Questionnaire

How often does the following happen?	Where I am now (Past 2 weeks)					Where I think I will be 6 months from now				
	Rarely	Infrequently	Sometimes	Often	Very Often	Rarely	Infrequently	Sometimes	Often	Very Often
<b>School</b>										
1. I get ready for school in the morning on my own.	1	2	3	4	5	1	2	3	4	5
2. I am late to school.	1	2	3	4	5	1	2	3	4	5
3. I complete homework assignments on my own.	1	2	3	4	5	1	2	3	4	5
4. I turn in homework assignments on time.	1	2	3	4	5	1	2	3	4	5
5. I wear the right clothes for school.	1	2	3	4	5	1	2	3	4	5
6. I have friends in my classes at school.	1	2	3	4	5	1	2	3	4	5
7. I join in group activities at school.	1	2	3	4	5	1	2	3	4	5
8. I get good grades in my classes.	1	2	3	4	5	1	2	3	4	5
<b>Home</b>										
9. I take responsibility for my own actions.*	1	2	3	4	5	1	2	3	4	5
10. I ask my parents to let me participate in activities (church events, community events, scouts, sports or school clubs).	1	2	3	4	5	1	2	3	4	5
11. I am OK with changes in family plans.**	1	2	3	4	5	1	2	3	4	5
12. I follow directions my parents give me.*	1	2	3	4	5	1	2	3	4	5
13. I complete chores at home that my parents give me.	1	2	3	4	5	1	2	3	4	5
14. I am able to listen to feedback from my parents.	1	2	3	4	5	1	2	3	4	5

Continued on next page...

Name: \_\_\_\_\_

ID#: \_\_\_\_\_

How often does the following happen?	Where I am now (Past 2 weeks)					Where I think I will be 6 months from now				
	Rarely	Infrequently	Sometimes	Often	Very Often	Rarely	Infrequently	Sometimes	Often	Very Often
15. When my parents ask me to do something I do it quickly.	1	2	3	4	5	1	2	3	4	5
16. When the family needs to go somewhere I am ready on time.	1	2	3	4	5	1	2	3	4	5
17. I follow the rules of my parents' house.	1	2	3	4	5	1	2	3	4	5
<b>Social</b>										
18. I see my friends outside of school (after school, on weekends, or in the summer).	1	2	3	4	5	1	2	3	4	5
19. I call/text/email/message my friends.	1	2	3	4	5	1	2	3	4	5
20. I say "please" and "thank you."**	1	2	3	4	5	1	2	3	4	5
21. I have a girlfriend.	1	2	3	4	5	1	2	3	4	5
22. I go on dates with girls.	1	2	3	4	5	1	2	3	4	5
23. I talk about subjects that other people are not interested in.	1	2	3	4	5	1	2	3	4	5
24. I am able to tell when someone is teasing.	1	2	3	4	5	1	2	3	4	5
25. I join clubs or social groups.**	1	2	3	4	5	1	2	3	4	5
26. I take turns in conversations.*	1	2	3	4	5	1	2	3	4	5
27. I hang out with other adolescents my age.	1	2	3	4	5	1	2	3	4	5
28. I stay calm when disagreeing with others.*	1	2	3	4	5	1	2	3	4	5
<b>Other</b>										
29. I say the same thing over and over.*	1	2	3	4	5	1	2	3	4	5
30. People say I ask too many questions.	1	2	3	4	5	1	2	3	4	5
31. I repeat one activity over and over.**	1	2	3	4	5	1	2	3	4	5

Continued on next page...

Name: \_\_\_\_\_

ID#: \_\_\_\_\_

How often does the following happen?	Where I am now (Past 2 weeks)					Where I think I will be 6 months from now				
	Rarely	Infrequently	Sometimes	Often	Very Often	Rarely	Infrequently	Sometimes	Often	Very Often
32. I shower when I need to (3 times a week or more)	1	2	3	4	5	1	2	3	4	5
33. I brush my teeth when needed (at least once per day)	1	2	3	4	5	1	2	3	4	5

What are 3 things you are good at doing?

What are 3 things you have problems with?

\* Question adapted from the SSIS

\*\* Question adapted from the BASC2

Name: \_\_\_\_\_

ID#: \_\_\_\_\_

## Parent Questionnaire

Please read the following statements and rate how often they apply to your child (in the study). Circle the number that corresponds to the frequency that most closely matches how often your child fits the statement. If you are unsure about an item give your best guess. For the items that rate where your child is currently think about events that have occurred over the past 2 weeks.



Name: \_\_\_\_\_

ID#: \_\_\_\_\_

## Parent Questionnaire

How often does the following happen?	Where my child is now (Past 2 weeks)					Where I think my child will be 6 months from now				
	Rarely	Infrequently	Sometimes	Often	Very Often	Rarely	Infrequently	Sometimes	Often	Very Often
<b>School</b>										
1. He gets ready for school in the morning on his own.	1	2	3	4	5	1	2	3	4	5
2. He is late to school.	1	2	3	4	5	1	2	3	4	5
3. He completes homework assignments on his own.	1	2	3	4	5	1	2	3	4	5
4. He turns in homework assignments on time.	1	2	3	4	5	1	2	3	4	5
5. He wears the right clothes for school.	1	2	3	4	5	1	2	3	4	5
6. He has friends in his classes at school.	1	2	3	4	5	1	2	3	4	5
7. He joins in group activities at school.	1	2	3	4	5	1	2	3	4	5
8. He gets good grades in his classes.	1	2	3	4	5	1	2	3	4	5
<b>Home</b>										
9. He takes responsibility for his own actions.*	1	2	3	4	5	1	2	3	4	5
10. He asks parents to let him participate in activities (church events, community events, scouts, sports or school clubs).	1	2	3	4	5	1	2	3	4	5
11. He is OK with changes in family plans.**	1	2	3	4	5	1	2	3	4	5
12. He follows directions his parents give him.*	1	2	3	4	5	1	2	3	4	5
13. He completes chores at home that his parents give him.	1	2	3	4	5	1	2	3	4	5

Continued on next page...

Name: \_\_\_\_\_

ID#: \_\_\_\_\_

How often does the following happen?	Where my child is now (Past 2 weeks)					Where I think my child will be 6 months from now				
	Rarely	Infrequently	Sometimes	Often	Very Often	Rarely	Infrequently	Sometimes	Often	Very Often
14. He is able to listen to feedback from his parents.	1	2	3	4	5	1	2	3	4	5
15. When his parents ask him to do something he does it quickly.	1	2	3	4	5	1	2	3	4	5
16. When the family needs to go somewhere he is ready on time.	1	2	3	4	5	1	2	3	4	5
17. He follows the rules of his parents' house.	1	2	3	4	5	1	2	3	4	5
<b>Social</b>										
18. He sees his friends outside of school (after school, on weekends, or in the summer).	1	2	3	4	5	1	2	3	4	5
19. He calls/texts/emails/messages his friends.	1	2	3	4	5	1	2	3	4	5
20. He says "please" and "thank you."**	1	2	3	4	5	1	2	3	4	5
21. He has a girlfriend.	1	2	3	4	5	1	2	3	4	5
22. He goes on dates with girls.	1	2	3	4	5	1	2	3	4	5
23. He talks about subjects that other people are not interested in.	1	2	3	4	5	1	2	3	4	5
24. He is able to tell when someone is teasing.	1	2	3	4	5	1	2	3	4	5
25. He joins clubs or social groups.**	1	2	3	4	5	1	2	3	4	5
26. He takes turns in conversations.*	1	2	3	4	5	1	2	3	4	5
27. He hangs out with other adolescents his age.	1	2	3	4	5	1	2	3	4	5
28. He stays calm when disagreeing with others.*	1	2	3	4	5	1	2	3	4	5

Continued on next page...

Name: \_\_\_\_\_

ID#: \_\_\_\_\_

How often does the following happen?	Where my child is now (Past 2 weeks)					Where I think my child will be 6 months from now				
	Rarely	Infrequently	Sometimes	Often	Very Often	Rarely	Infrequently	Sometimes	Often	Very Often
29. He says the same thing over and over.*	1	2	3	4	5	1	2	3	4	5
30. People say he asks too many questions.	1	2	3	4	5	1	2	3	4	5
31. He repeats one activity over and over.**	1	2	3	4	5	1	2	3	4	5
32. He showers when he needs to (3 times a week or more)	1	2	3	4	5	1	2	3	4	5
33. He brushes his teeth when needed (at least once per day)	1	2	3	4	5	1	2	3	4	5

What are 3 things he is good at doing?

What are 3 things he has problems with?

\* Question adapted from the SSIS

\*\* Question adapted from the BASC2

## APPENDIX E

### PARENT INTERVIEW

**Parent Survey**Contact Information

Child's Name: \_\_\_\_\_

Mother's Name: \_\_\_\_\_

Father's Name: \_\_\_\_\_

Street Address: \_\_\_\_\_

City: \_\_\_\_\_ State: \_\_\_\_\_ Zip: \_\_\_\_\_

Best Contact Phone Number(s): \_\_\_\_\_

Demographic Information<sup>a</sup>

Your Name: \_\_\_\_\_

Relationship to Child: \_\_\_\_\_

Child's Birth Date: \_\_\_\_\_ Child's Age: \_\_\_\_\_ Current Date: \_\_\_\_\_

Child's Gender: \_\_\_\_\_ Child's Ethnicity: \_\_\_\_\_

Grade in school (6<sup>th</sup>, 12<sup>th</sup>, etc.): \_\_\_\_\_ How many siblings does this child have? \_\_\_\_\_

Mother's Occupation: \_\_\_\_\_ Mother's Education: \_\_\_\_\_

Father's Occupation: \_\_\_\_\_ Father's Education: \_\_\_\_\_

With whom does the child live?

\_\_\_\_ Biological Parents      \_\_\_\_ Step Parents      \_\_\_\_ Grandparents

\_\_\_\_ Foster Parents      \_\_\_\_ Adoptive Parents      \_\_\_\_ Single Parent

\_\_\_\_ Other: \_\_\_\_\_

List first names, ages, and relationships of people living with the child (use back if necessary) <sup>c</sup>:

<u>First Name</u>	<u>Age</u>	<u>Relationship</u>
_____	_____	_____
_____	_____	_____
_____	_____	_____
_____	_____	_____
_____	_____	_____
_____	_____	_____

### Family History

Is there any history of mental health disorders on the mother's side of the child's family? \_\_\_\_\_ If Yes, please explain: \_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

Is there any history of mental health disorders on the father's side of the child's family? \_\_\_\_\_ If Yes, please explain: \_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

Is there anyone in the child's family (not including the child) who has been suspected of or diagnosed with an autism spectrum disorder (autism, Asperger's, or Pervasive Developmental Disorder)? \_\_\_\_\_ If Yes, please explain (who was it, when did it happen, and who suspected or diagnosed): \_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

### Developmental History<sup>a</sup>

What serious illnesses, accidents, or operations has your child had (including hospitalizations for physical injuries and emergency room visits)?

Problem	Age
_____	_____
_____	_____
_____	_____
_____	_____

Has your child ever had:

_____ Seizures	_____ Vision Problems	_____ Allergies
_____ Periods of Unconsciousness	_____ Hearing Problems	_____ High Fevers
_____ Head Injury	_____ Speech Problems	_____ Other Medical Problems

If Yes to any of the above, please explain:

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### Educational History<sup>b</sup>

What age did your child start school? \_\_\_\_\_ Has your child dropped out of school? \_\_\_\_\_

Has your child ever been advanced a grade? \_\_\_\_\_ Which grade? \_\_\_\_\_

Has your child ever repeated a grade? \_\_\_\_\_ Which grade? \_\_\_\_\_

What is your child's current GPA? \_\_\_\_\_

Has your child ever received special education? \_\_\_\_\_ If yes, which services  
(speech, resource, guidance, OT, ect.) and when? \_\_\_\_\_

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Has your child ever had a 504 plan? \_\_\_\_\_ If yes, what accommodations did your  
child receive?

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*The following are questions for the parent interview. You DO NOT have to write any answers to these questions unless you would like to.*

### **Parent Interview**

Go over Parent Survey and ask about any significant events or information.  
Make sure information is clear.

Family History Notes

Developmental History Notes

Educational History Notes

Autism

Has your child ever been suspected of or diagnosed with an autism spectrum disorder (autism, Asperger's, or Pervasive Developmental Disorder)? \_\_\_\_\_

If Yes, what happened, when did it happen, and who suspected or diagnosed:

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If your child has been diagnosed with or has been suspected of having an ASD:

What age did you or someone else suspect that your child had an ASD? \_\_\_\_\_

What age was your child diagnosed with an ASD? \_\_\_\_\_

Psychiatric Diagnoses and Medications

1. What medications does your child currently take? What are they intended to treat? <sup>d</sup>

Drug/Dose

Behavior or symptom intended to treat

_____	_____
_____	_____
_____	_____
_____	_____

Any past medications for psychiatric problems? And what were they for?

2. Has your child ever been diagnosed with any psychiatric/psychological condition other than an ASD? (List each diagnosis, provider who gave it and approximate date) <sup>d</sup>

<u>Diagnosis</u>	<u>Provider</u>	<u>Date</u>
_____	_____	_____
_____	_____	_____
_____	_____	_____
_____	_____	_____

What age did you child first start experiencing psychological problems? \_\_\_\_\_

When did you first suspect your child had psychological problems? \_\_\_\_\_

#### Psychiatric Treatment History

3. What ***outpatient (no overnight stay)*** psychiatric treatment (including counseling) has your child had in the past? List most recent first. <sup>c</sup>

<u>Date/ Age</u>	<u>Length of Treatment</u>	<u>Symptoms or Condition</u>	<u>Treatment/Location</u>
_____	_____	_____	_____
_____	_____	_____	_____
_____	_____	_____	_____
_____	_____	_____	_____

4. What ***inpatient (spent the night in the treatment facility)*** psychiatric treatment/hospitalization has your child had in the past? List most recent first. <sup>c</sup>

<u>Date/ Age</u>	<u>Length of Treatment</u>	<u>Symptoms or Condition</u>	<u>Treatment/Location</u>
_____	_____	_____	_____
_____	_____	_____	_____
_____	_____	_____	_____
_____	_____	_____	_____

5. Age of first outpatient treatment \_\_\_\_\_ Age of first psychiatric hospitalization \_\_\_\_\_  
 Number of psychiatric hospitalizations \_\_\_\_\_<sup>c</sup>

6. Reason for latest psychiatric treatment: \_\_\_\_\_

### Psychiatric and Behavioral Symptoms

7. Does your child ever get so angry that he destroys property? \_\_\_\_\_ When?<sup>d</sup>

\_\_\_\_\_

\_\_\_\_\_

8. Is your child ever verbally or physically aggressive towards people or animals? \_\_\_\_\_

When? \_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

9. Has your child ever threatened or attempted suicide? \_\_\_\_\_ When and what happened? \_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

10. Has your child had any involvement with law enforcement? \_\_\_\_\_ When and what happened?

\_\_\_\_\_

\_\_\_\_\_

### School Adaptation and Social Relations

12. **School.** Ask about: (a) Problems at school; (b) Complaints from teachers about child's behavior; (c) Suspensions and detentions; and (d) Likes and Dislikes.<sup>c</sup>

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

13. **Peer Relations.** Ask about: (a) Best Friend(s); (b) Relations with peers at school; (c) Relations with peers in home neighborhood; (d) Activities with friends; and (e) Problems (e.g. teased, in fights). <sup>c</sup>

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14. **Family relations.** Ask about: (a) Mother-Child relationship; (b) Father-Child relationship; (c) Sibling relationships; (d) Extended Family/Social Supports; and (e) Current or Past DCFS involvement. <sup>c</sup>

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15. What does your child do in his free time? Does he have any hobbies? What are they? Are there any specific activities associated with his hobbies? <sup>d</sup>

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16. Does your child belong to any church, special interest club, sports team, or service organization? How much time per week does he spend in activities related to this group? <sup>d</sup>

Group

Time per Week

<hr/>	<hr/>
<hr/>	<hr/>
<hr/>	<hr/>

17. Is your child interested in having more social relationships than he currently has?  
How do you know? <sup>d</sup>

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18. Has your child ever dated or had a romantic relationship? Did he initiate the  
relationships? What were the durations of the relationships and why did they end? <sup>d</sup>

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19. Is your child interested in dating or having a romantic relationship (if they don't  
currently have one)? How do you know? <sup>d</sup>

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20. Is there anything else about your child you would like us to know?

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<sup>a</sup> Items adapted from Gabrielsen (2009)

<sup>b</sup> Items adapted from Dekyzer (2004)

<sup>c</sup> Items adapted from KSADS-PL

<sup>d</sup> Items adapted from Farley (2009)

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